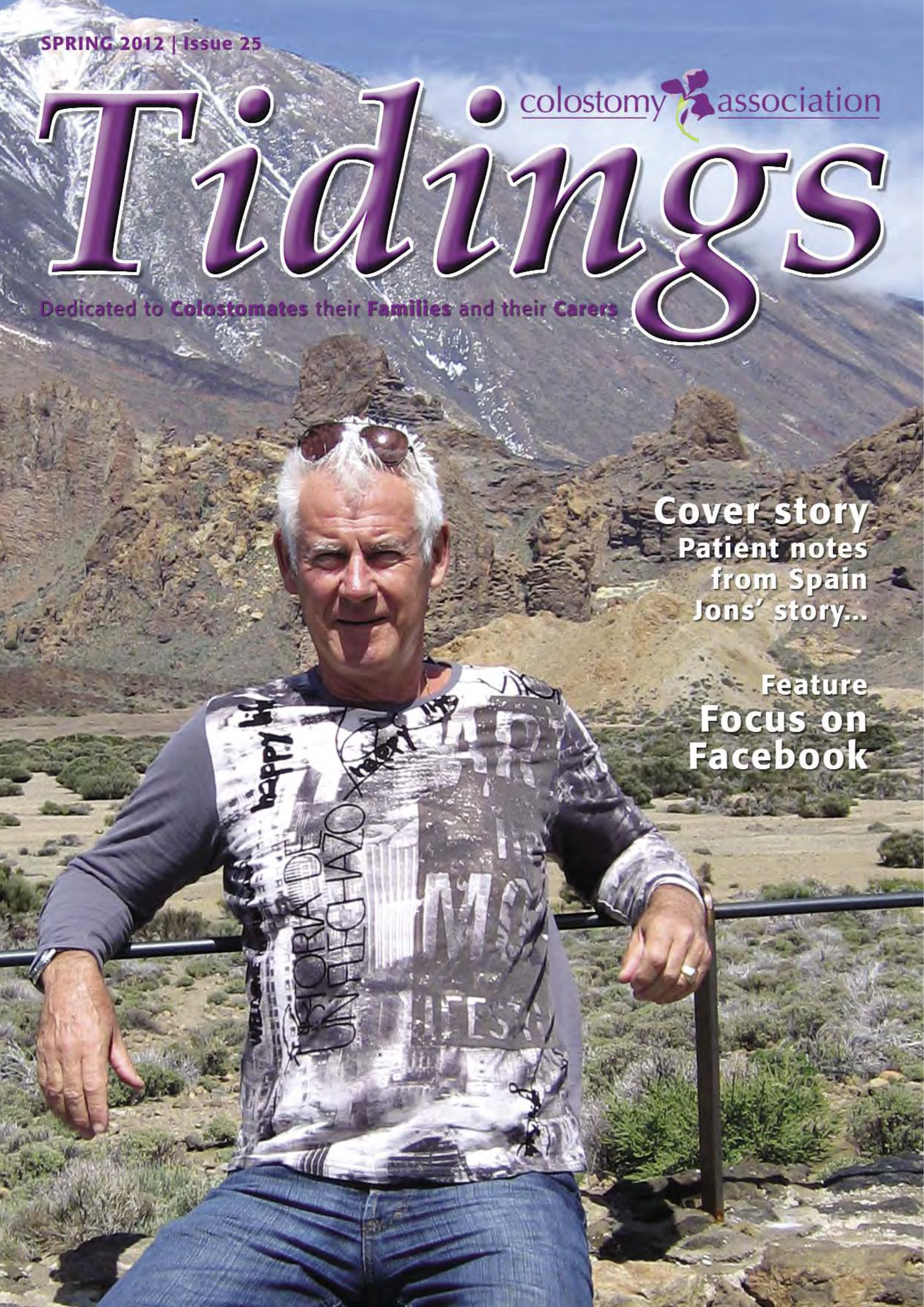
SPRING 2012 | Issue 25

colostomy association

Tidings

Dedicated to **Colostomates** their **Families** and their **Carers**



Cover story
Patient notes from Spain
Jons' story...

Feature
Focus on Facebook

Have Your Say

Join us...

...at a venue near you and tell us what your thoughts and feelings are about life with a stoma.

What you can expect from the events

- Opportunity to speak to stoma care nurses
- Talk to us to let us know your thoughts and feelings about life with a stoma and how we can help
- Meet members of patient groups
- A pleasant day out with lunch/afternoon tea/coffee and cake available (depending on which event you attend)
- Being held at a range of convenient and beautiful locations across the country
- Meet fellow ostomates

Register on-line where you can view all the events, sign up for email updates for future events and request FREE samples.

Register your interest now at **www.yoursay.me.uk**

Hollister

YourSay .me.uk

welcome to SPRING

Did you know...

The Colostomy Association have produced a....**Photo Identity Card**

IDENTIFICATION CARD

Disability Rights UK

The cardholder has a medical condition and needs urgent access to disabled facilities

ID card Number

123e45

If found, please return to:
CA, 2 London Court, East Street, Reading, RG1 4QL

The card can be carried with you so that if you are ever challenged about your use of a disabled lavatory you can provide proof of need. The card displays the Disability Rights UK logo and explains that the card holder has a medical condition and needs urgent access to disabled facilities.

To find out more...contact CA head office on: 0118 939 1537

Welcome to the spring issue of Tidings...

The dark days of winter are over, the hour has changed – and thankfully good old British Summer Time (BST) is with us once more! From now on we can look forward to lighter evenings, warm breezes on our faces, the outdoors and, Yes! that holiday we promised ourselves! What a wonderful thought!

2012 is such a special year for our country! The date of the London Olympics is creeping ever nearer! There is no doubt that we will be treated to an exceptional event... probably, the greatest show on earth!

The Olympics are truly inspirational – I don't just mean the sporting prowess of the incredible athletes competing to win gold, silver or bronze medals! The games unite millions across the globe! They offer us an opportunity to focus on the best of human qualities...of endurance, courage and tenacity!

The 'real lives' stories in every issue of Tidings contain these human qualities and give an intimate insight into very personal journeys – of human survival, of determination, of medical advances, that when all are brought bear can and often do triumph over life threatening accidents or illnesses. The games shine out like a beacon, showing us that we too are achievers, we can clear the hurdles that life places in our path, we too can pass the finish line and take gold!

I would like to thank everyone who has shared their experiences with Tidings readers and I appreciate that it may have been difficult for you to do! But I would encourage others to step forward as there is no doubt that your stories have an immense impact on and make difference to the colostomates who read them, as the feedback from the many letters and emails received from Tidings readers' confirms.

In this issue of Tidings you will find all your regular articles, and more besides, you might even find some surprises too! The CA News page gives an update on staff changes and much more! There is a special feature on Facebook, an article from Duncan Wells CA Trustee introduces you to the Facebook 'Wall' and the intricacies of managing security on your CA Facebook account and another from CA Facebook administrator and volunteer Helen McTurk, explains the benefits of joining the CA Facebook group! If you are not a great fan of technology or have doubts about joining Facebook maybe this is the time to set them aside and get involved! It would be great to hear from those of you who give it a try!

If Facebook is not for you..I hope you enjoy reading the many other articles inside this issue...like the one from 'support group' guru...Alfred Levy who shares his patient journey and reveals – how, with perseverance, he set up his own local patient support group...it's a fascinating read!

On behalf of the Editorial team enjoy this issue of Tidings. I encourage YOU to get involved with Tidings...YOU make it what it is...YOUR Magazine!

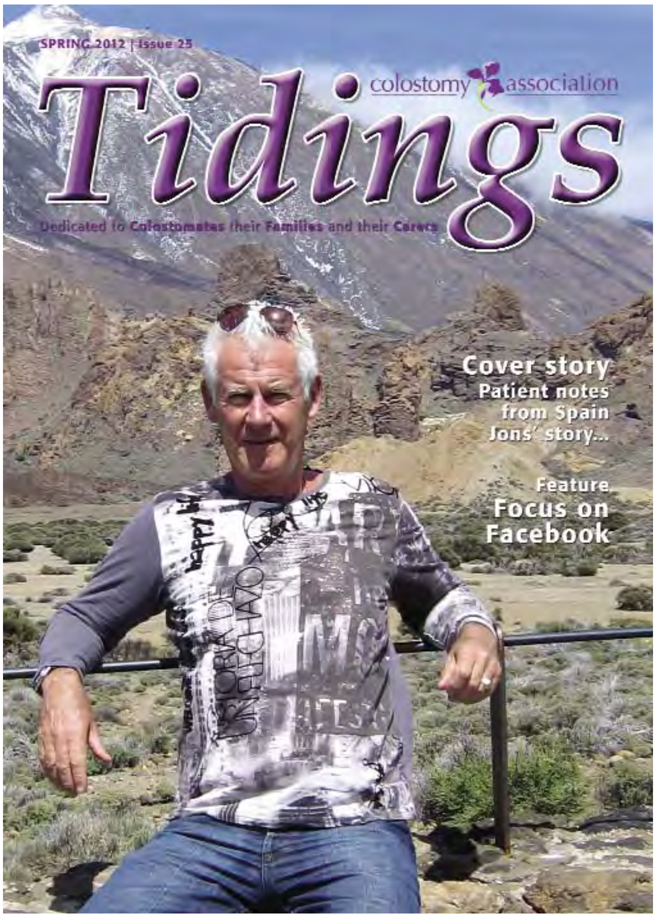
Jane

editor@colostomyassociation.org.uk

PS.If you would like to get in touch with the Colostomy Association or Tidings please take a look at Page 6.

inside……
all your regulars

cover story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real lives...

health...

travel...


colostomy association

Travel Certificate
for people with
a colostomy

Freephone helpline
0800 328 4257

www.colostomyassociation.org.uk

Don't forget your new look travel certificate this spring...

Contact CA office on 0118 939 1537

support...

interest...

How to get in touch...with the Colostomy Association and Tidings...

About...the Colostomy Association

The Association 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.

How to become a member of the Colostomy Association...

Simply contact us by post:
Colostomy Association
2 London Court,
East Street, Reading RG1 4QL

By telephone:
General Enquires: 0118 939 1537

Stoma care queries only:
Freephone Helpline: 0800 328 4257

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

Find us on Facebook:

Find us on Facebook

Simply visit our **website** and **register** at:
www.colostomyassociation.org.uk

Don't delay... Donate Online today!

There are **NOW two ways** to **donate online...**

1

Visit the **CA website** and **simply click** on the **donate panel** on the **home page.**

JustGiving

2

Visit the **Just Giving home page** you will see a search panel **'Find a Charity'** type in **Colostomy Association.**

Tidings is YOUR Magazine...

Editorial Submissions:
Tidings is a quarterly publication. Your contributions to Tidings are always welcome. If you have a story, article or letter that you would like featured in the magazine we would like to hear from YOU!

If you have an idea for an article and would like to discuss this with the Editor or would like help writing your story please get in touch. We will always do our best to include your contributions in the next issue of Tidings or will hold them back for a future issue. When submitting your information don't forget to supply your name, address, phone number and e-mail address if you have one.

Please include any relevant photos or illustrations as these really help to bring YOUR magazine to life! You can send these as prints or digital images.

Feedback... We are always trying to improve your Magazine and welcome your feedback. Enjoy this issue of Tidings we look forward to bringing you the next edition...

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

- **Images should be in RGB mode**
- **Images should not be less than 1500 pixels x 1200 pixels at 300 pixels per inch (equal to 12.5cm x 10cm).**
- **File sizes not less than 10Mbytes uncompressed**
- **Images in Tiff with LZW compression or JPEG format.**
- **For scanned images please set at 300ppi in RGB mode and scan original @100%.**

Advertising Enquiries:
For a media pack and advertising rates.
Contact Jane Wood: 0118 983 6226

Publication:

Spring	April	2012
Summer	July	2012
Autumn	October	2012
Winter	January	2013

EDITORIAL TEAM

How to contact the Editor

By letter write to:

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

By telephone via CA Office:
0118 939 1537

or e-mail the editor direct:
editor@colostomyassociation.org.uk

or e-mail:
cass@colostomyassociation.org.uk

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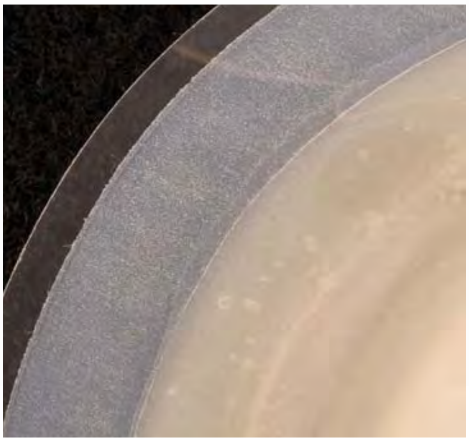



OakMed
Freephone 0800 592786
www.oakmed.co.uk

NEWS update from the CA office...

Changes to staff...

Richard Bray who has been our manager for nearly three years has decided to pursue other interests and resigned with effect from the end of January - his successor is Sue Hale.

Sue Hale initially joined the CA as interim general manager to cover Richard's ill health; she has now been appointed to this role on a permanent, full time basis. Sue has a sound beneficiary focus background from various previous charitable roles and has a broad range of experience covering marketing, bid writing and event organisation as well as managing staff and international volunteers. Sue has set up a fundraising working party focussed initially on raising money for a variety of much needed IT related equipment and other general fundraising activities.

Chris Williams joined the team as a part time administrator in January 2012 working Tuesday to Thursday and has quickly settled in. Chris has extensive experience in administration in a variety of organisations, including an Army medical centre. Chris is dealing mostly with the 500 Club, the database, day to day enquiries and the CA website.

Jo McKenzie continues to be an energetic and enthusiastic team member in her full-time administrator capacity. Jo has recently taken on full responsibility for the CA volunteers , so is busy liaising with existing members as well as recruiting and arranging training for new voluntary helpers. Jo is planning the next training course for our potential volunteers which should take place this Summer in the northern half of England.

CA Facebook Group...

The CA Facebook facility is proving very popular and has been changed so that it is now a private group. Participants can more openly discuss their problems and share their experiences. If you would like to benefit from this interactive, supportive online community, please go to www.facebook.com to join. Please mention you are a Tidings reader and you will be invited to join immediately! You can learn more about the Group and Facebook in this issue of Tidings on Pages 30-34.

CA launches New Research Fund...

Following the sad loss of Bob Buckley last autumn (see page 10 of Tidings 24) we have been amazed how many donations were received through a Just Giving webpage kindly organised by Bob's son, Kevin Buckley.

As a result, and supported fully by his wife, Margaret, The Bob Buckley Research Fund has been created by the CA in his memory and more than £1,100 has already been allocated.

This Fund will be used for specific research projects and will be a living legacy for Bob's family, while benefitting others longer term. More announcements on this Fund will follow in future issues of Tidings.

If you would like to donate to this cause in Bob's memory, please send a cheque to the CA with a note marked for the Fund or go to: www.justgiving.com/kevin-buckley78.

More information will follow on this wonderful legacy in honour of Bob in the years to come! He is sorely missed.

Calling Scotland...

We currently only have one volunteer in Scotland representing us at various open days so we desperately need more volunteers who could help ease the workload. We supply CA branded table cloths and literature for the stand and our existing volunteers very much enjoying meeting fellow ostomates and offering support. Please get in touch with Jo McKenzie to find out more about what's involved. The volunteer recruitment process is fairly straightforward – a simple form and an informal chat. We hope to hear from you soon.

Tidings...

The weeks around the issue date of Tidings is always a busy time in the CA Office. Many more calls are received and requests for literature and telephone support increase exponentially. This demonstrates the enormity of the impact Tidings has on its readership. Please bear with us at these busy times.

Sue Hale
CA General Manager

Don't delay... Donate Online today!

There are **NOW two ways** to **donate online...**

1

Visit the **CA website** and **simply click** on the **donate panel** on the **home page.**

JustGiving

2

Visit the **Just Giving home page** you will see a search panel **'Find a Charity'** type in **Colostomy Association.**

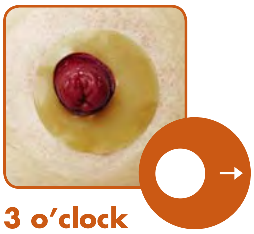
World Beating Innovation

NEW Dansac Seal – redefining leak prevention.

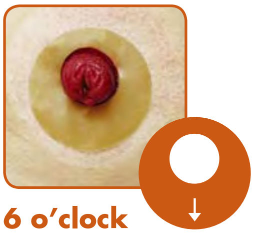
In 2012 Great Britain will welcome the world's greatest performers to its shores. Dansac already has its own gold medalist, the 'Dansac Seal', setting new standards for innovation and performance.

The unique off-centre starter hole on the Dansac Seal, makes it possible, by turning the seal in any direction, to get extra protection where it is needed most. This provides more barrier material at the crucial 3, 6 and 9 o'clock positions, where skin folds or retractions may make it difficult to achieve a good seal between the stoma and the skin.

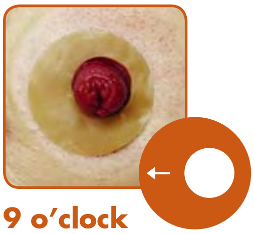
And with a choice of four different sizes available, you can be sure to find a seal that's the perfect fit for you!



3 o'clock



6 o'clock



9 o'clock

Please send me a **FREE SAMPLE** of Dansac Seal

I have a: ☐ Colostomy ☐ Ileostomy ☐ Urostomy

Type of appliance ☐ 1 piece ☐ 2 piece

My stoma size is ______________ mm

Simply fill in the reply coupon, pop it in an envelope marked: **FREEPOST DANSAC** No stamp or further address details are required.

Name ______________

Address ______________

______________ Postcode ______________

Tel ______________

Email ______________

REF 1042

DANSAC **SEAL**

dansac

Pathways to a Urostomy… and a Colostomy

A serious fall in her teens – a compression fracture of the first vertebra affecting both bladder and bowel – a failed bladder operation and incontinence...led Margaret Florey to gladly accept her first stoma, a urostomy. Later having held down a full time job for more than twenty-four years problems began again...this time it was her bowel...

My story starts in 1962 when I was fourteen years old. I lived in a residential care home and didn't have contact with my family. One day I was sat on the sill of an open window and I accidentally fell out onto my back. I sustained a compression fracture of the first lumbar vertebra with paraplegic signs in the lower limbs. I was sixteen before I was able to walk again, with callipers on both legs.

My bladder and bowel were also affected by the fall. An operation on my bladder failed so I had to have a catheter attached to a leg bag and this worked for a while. I had to manually evacuate the bowel and this I managed for many years.

However, my bladder catheter kept falling out, so that left me incontinent. When I was seventeen years old I saw a consultant who offered to give me a stoma so that the urine would go into a pouch. Back then they were black rubber bags and separate cream-coloured flanges attached with double-sided plasters. They came in boxes of three: one in use, one washed and hanging up to dry, the other a spare. Cleaning and reusing would cause them to perish, so after about three months you could ask for a new box. There were no night drainage bags then. I would have to get out of bed to empty the bag during the night. However, I was pleased to accept this and my first stoma worked very well.

When I was twenty-one I started work as a finance clerk at British Bakeries. Having a urostomy didn't cause me any problems. I told my manager about it, but not the rest of the staff, apart from one close friend. In 1971 I developed a rash and went to see my stoma care nurse who told me about other bags that were available. They made my life so much easier.

When I was twenty-one I started work as a finance clerk at British Bakeries. Having a urostomy didn't cause me any problems. I told my manager about it, but not the rest of the staff, apart from one close friend.

I worked full time, leaving home at 7.45am and getting home at 5.45pm, for more than twenty-four years. Then the trouble with my bowels began to get worse. I became very constipated and my GP gave me a prescription for laxatives. However, I still had long periods of constipation followed by days of diarrhoea. I had lost control of my bowel: I had no feeling in it so I didn't know when it would empty. My GP retired me from work on health grounds.

After that, I stopped going out much because I was either in discomfort from constipation or I was afraid that I would have an embarrassing accident. This continued for years before I decided to go to a different GP in the same practice and made a request to see a bowel specialist. After a few months I got an appointment with a medical specialist at my local hospital. He arranged for me to have an X-ray

> I still think that having a colostomy was the best decision I have ever made. Now I don't think twice about going on a bus and am able to take my "great nephew", Jacob, out on day trips.

on my bowel. I couldn't take laxatives for six days until I went back for another X-ray to see how the bowel had worked. I knew that the bowel hadn't emptied at all and was glad to get home to take laxatives. Some weeks later I received a letter from the local hospital to say that they couldn't treat me, as it was too complicated for them and they would refer me to St Mark's Hospital.

My appointment came for 21st April 2008. I saw Professor Christine Norton and told her about my problem. I was so relieved when she said she understood and could help me. Tests showed that I had complete saddle anaesthesia, a small mucosal prolapse, no squeeze increment and complete absence of rectal and anal sensation.

The professor offered me a new treatment at that time. It was called Peristeen anal irrigation and involved introducing water into the rectum. I tried this treatment for six months but unfortunately it didn't work. I was so frustrated that the bowel wouldn't empty, as it should have done. So I returned to St Mark's for an appointment with a consultant surgeon who said he would give me a loop colostomy.

In May 2010 I went in for the operation, which was done by keyhole surgery. It was so different from when I had my urostomy forty-four years before. Then I remember not being able to eat or drink and staying in hospital for a long time. When I came round from the operation this time I was given water to drink and had breakfast the following morning. Four days later I was home, very happy with my second stoma.

For my urostomy I use a one-piece bag and change it every two days. I know how important it is to drink plenty of fluid so I have to drain the urine out through the tap at the bottom many times a day. For my colostomy I also use a one-piece drainable and change that every day. I still suffer from constipation, but have been able to cut down on my laxatives so now I only take two each day.

Of the two stomas the urostomy is the easiest to manage – I have had very few problems with that. With the colostomy I had the usual "teething problems". At first my stoma kept changing shape and size which led to leaks. My stoma nurse helped me to measure the stoma and cut the flange to the correct size. When it settled down I was able to send a template to my delivery company who now cut the flanges for me. I also experienced pancaking and found the one thing that helps is the special ostomy gel. I squirt a bit into the bag and rub it around before I put it on and this helps the motion to slip down to the bottom. I have also had granulomas, small nodules around the edge of the stoma, but these have been cauterised with silver nitrate and have not come back. My stoma nurse was a great help and I learnt a lot from Tidings. I find it useful to go to open days that are organised locally, either by manufacturers or our stoma nurse team at East Surrey Hospital.

I knew that I would have a discharge from my rectum but I didn't get any until about three months after the op. As I found this hard to deal with my GP wrote to St Mark's and requested another appointment. The consultant looked in my rectum and told me that because of the problems with the muscles and nerves I'd had in the past the discharge had stayed in my rectum and become infected. I had two options. I could have my rectum removed but it was major surgery and had complications or I could flush out the rectum. I chose the latter. My caring stoma care nurse brought me the equipment and showed me what to do. I now do this once a month.

Recently I noticed that my stoma was increasing in size and was very floppy and uncomfortable and I have been told it has prolapsed. My surgeon said he could refashion it or alternatively I could wait and see how it goes. I chose the latter and we agreed that if I wanted an operation I would go to see my stoma nurse and she would talk to him.

Despite this I still think that having a colostomy was the best decision I have ever made. Before my colostomy operation I would be at home in pain with constipation or, afraid to go out in case of an attack of diarrhoea. Now I don't think twice about going on a bus and I am able to take my "great nephew", Jacob, out on day trips. I can visit friends: one of them said to me recently, 'Do you know, you haven't been ill for a whole year.'

Margaret Florey

We need YOU!...Fundraising is an immensely **important source of income** for the **Colostomy Association**...as we rely solely on donations to continue our work of **giving support to colostomates...**

Donations
When sending your donation/s **please mark your letter/cheque** with **Tidings Issue 25....**
Thank you!

Bowling for funds...

Last November, I organised a Bowls Match between the two local clubs I play for, Erewash Indoor Bowls Club where I live in Long Eaton, Nottingham, and the other club that I play for Attenborough Village Bowls Club, Nottingham to raise funds for the Colostomy Association.

Erewash Indoor Bowls Club has been running for several years and they are always very pleased to support charities. They have a good many members and if a charity event is staged, they are only too willing to take part to raise funds and awareness.

When I began planning the event, I discussed the idea with Club Manager, Mr John Arnett. From the outset John and later the board were very supportive, and I have to thank them for their help!

I was hopeful that the event would be of interest to the players so kept a close eye on the list of members willing to support and play. To begin with just 2 signed up, then...6 then 10! When I checked again there were some 36 names on the list!

Attenborough were no different. I phoned the members inviting them to participate and everyone who could play said they would, 54 members agreed to play!

Match day came and although it was a little chaotic at first, the teams were sorted out and it was time to begin. As it turned out, there were enough players to play 8 rinks of 6. About 10 minutes before we got underway, a reporter from the local paper arrived, (which I had no idea about) and took a group picture and details of the event for publication.

We began with a ‘Spider’- this is where the Jack is placed in the centre of the playing area and players spread out around it. Each player sends a wood towards the Jack at the same time! The nearest wood to the Jack, when all the woods have stopped, wins a prize. For this Spider...the prize was a bottle of whisky (donated by the club). The winner of the whisky was Erewash Club President - Audrey Porter! It’s a great way to start off an event like this - it’s really fun!

Next, it was time to get serious...the matches began! Two sides playing for a trophy - to keep! Every player did their very best for their club in the hopes of winning! Bowls is no different from any other sport in that there are good times and not so good times during play, so for a while scores were close. After 10 ends we had a break for tea and biscuits and the raffle!

The raffle was supported by very generous donations from club members, the bowls clubs and local businesses (everyone I asked came back with prizes or a promise of a cash donation). With tea and the raffle over, the match was played to its conclusion.

It was a well-fought match and the eventual winners were Erewash! After the match I presented Audrey (the Erewash Club President) with the trophy which was accepted with pleasure and will remain alongside the other trophies that have been won by Erewash in the past. There are a good number too, I may add.

As for Attenborough, well, they were, as usual gracious in defeat (though that’s not to say they always lose by any means). They congratulated Erewash on their good performance.

And so ended a very nice afternoon of playing Bowls. The money raised was totalled up and I had the greatest pleasure telling everyone that the amount raised was…£130.00!

My grateful thanks go to the players from Erewash and Attenborough Bowls Clubs for their time, support and help. It would not have been possible without them! I really hope that this will become an annual fundraising event for the Colostomy Association!

If anyone out there reading this plays bowls for a club anywhere in the country I can assure you that it’s a really fun way of raising money for the Association. If you have not done this yet, I recommend it and if enough of you get into it, who knows where it will end and how much money we colostomates can raise together.

Yours,
TS

If you are having a fundraiser for the Colostomy Association write in and tell us about it...you could be featured here!

Special thanks goes to... the Donald Forrester Trust who recently donated £5,000 to CA

Thank you everyone for your kind donations

About the Donald Forrester Trust… In 1934 the late Donald Forrester set up Films & Equipments Limited as a manufacturing company supplying the film industry. After the sale of the business in 1960, the company became, and remains, an investment company. Mr Forrester died on 25th February 1985 and his widow decided to set up the Donald Forrester Trust in his memory.

The **Colostomy Association** would like to take this opportunity to thank the **Donald Forrester Trust** for their kind donation of **£5,000.**

Would you like to plant a tree to commemorate a special person or event?

If so, we have several varieties available for a suggested donation of £10.00 each, inclusive of P&P. A limited number of saplings were kindly donated to the CA and they are ideal for planting in either a garden or an allotment.

Contact CA head office for further details: 0118 939 1537

Save your used stamps for CA!

It doesn't matter that they have already been used, or if they are everyday first or second class stamps. If the CA can collect enough of them they will help to raise funds! Stamps are sold by weight (per lb/kilo). The value of a stamp does not matter, so 1p stamps can be grouped together with £1 stamps. If the CA identifies any valuable stamps they will be sold for a higher price. Please encourage your friends and family, at home and abroad, to save their stamps for the CA!

Contact CA head office for further information 0118 939 1537.

CharityFlowers.co.uk

Provided by Guernsey Flowers Ltd

Guernsey Flowers Limited based in the Channel Islands of Guernsey have been involved in the Flowers by Post Business for many years.

Guernsey Flowers Limited manage the **www.charityflowers.co.uk** website and call centre and provide and pack the flowers from purpose built premises.

By choosing to purchase your flowers via the charity flowers website you will be giving more than just beautiful flowers...You will be helping the **Colostomy Association** as 15% of the retail price of each order goes to the charity.

Send for your FREE catalogue today or visit: www.charityflowers.co.uk or telephone 0870 530 0600

Please note: When ordering please quote 'COL' - many thanks.

500 Club... December 2011 Draw Winners!

Mrs S M Mayston	£1000.00
Mrs A Stone	£ 348.00
Mr P Collins	£ 174.00
Mrs H Vickers	£ 69.60
Anonymous	£ 69.60
Mrs E Hancock	£ 69.60
Mrs M A Bebbington	£ 34.80
Mr A Bright	£ 34.80
Mrs K Barnes	£ 34.80
Mrs C Richards	£ 17.40
Miss S J Hall	£ 17.40
Anonymous	£ 17.40

Dear CA,

Orbit Property Management would like to give our Annual Charitable donation...to your charity!

Please accept our company's annual charitable donation £1,001.00 to support your work.

Yours
N D P

Legacies...

Mr R Clark	£ 5965.50

Thank you

Roy Clark lived with his colostomy for 32 years and was grateful for the support and information given to him by the Colostomy Association during that time. Roy was well known in his community in Frome, Somerset and kindly named the Colostomy Association as one of his beneficiaries.

Kind thanks to everyone who wrote in with donations...

Update on stoma care products and services

Tidings is always **interested to learn about new stoma care products and services**...from **manufacturers and suppliers. Colostomates...**if you have found **a stoma care product** or **service beneficial to 'living with a colostomy' please let Tidings know**. **YOUR findings could make ALL the difference to other colostomates.**

Comfizz scoops high profile healthcare award

Comfizz Ltd is celebrating after picking up a prestigious award at the British Healthcare Trades Association (BHTA) annual awards dinner. The evening was compared by Angela Rippon with sports presenter Garry Richardson. The award, presented to Comfizz was for their levels 1, 2, 3 stoma support wear range.

Ray Hodgkinson, Director General of the BHTA, congratulated the team at Comfizz and commented that the award was richly deserved. "The awards we present each year are given only after a rigorous process involving a panel of judges and the winners represent excellence in what is an important and growing marketplace.

For more information about Comfizz visit: www.comfizz.com

Looking after your skin made easier by Salts Healthcare

Leaks, adhesive residue and constant pouch changes can all lead to sore skin, but Salts Healthcare has introduced two exciting new products to help:

New WipeAway Adhesive Remover Spray, in a handy size 50ml bottle, is alcohol free and quick and easy to apply for stress free adhesive removal.

PeriPrep Sensitive No-Sting Barrier Film now comes in a **new 1ml Foam Applicator** providing accurate application and maximum protection.

OakMed's hydrocolloid soft convex closed bag is now available on prescription...

The alginate closed bag will be available soon. The hydrocolloid is soft and flexible with a unique tapered border and superior adhesion for a superb fit and greater comfort.

For advice or samples please phone OakMed on Freephone 0800 592 786

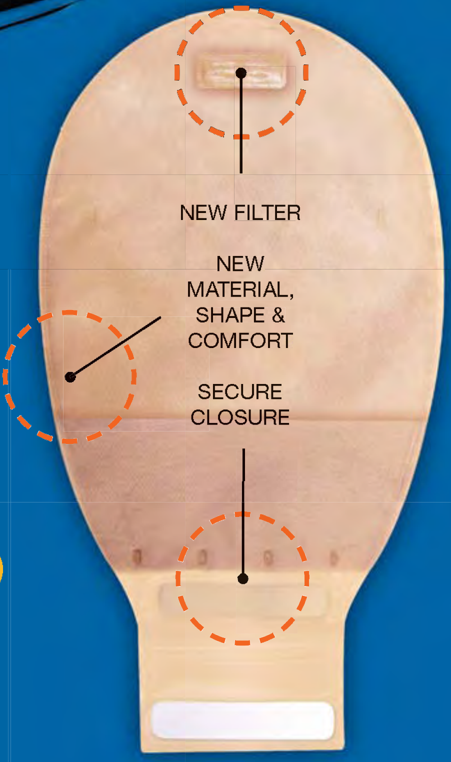
Independence products... improves two products - ARW1: Adhesive remover wipe and BW1: Barrier Wipe

Independence Products Ltd have recently made improvements to two of their products **ARW1: Adhesive remover wipe and BW1: Barrier Wipe**, not only has the quality of the tissue improved but more liquid is also being used so that you get a more effective result from one wipe.

Both wipes designed for stoma patients with the intention of preventing your skin from being irritated when applying and removing your appliances. The barrier wipe will leave a protective barrier film on the skin before you apply your appliance and the adhesive remover wipe will aid with the removal of the sticky residue left behind.

Both of these products are available on prescription and can be ordered via your normal supplier.

For a free sample of either product please contact the friendly staff here at Independence Products Ltd on 0115 9757254 or email us at: samples@independenceproducts.co.uk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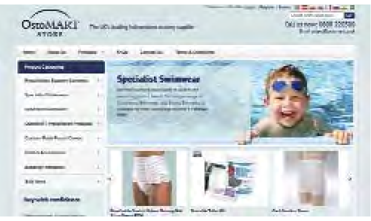
NEW MATERIAL, SHAPE & COMFORT
SECURE CLOSURE

NEW...OstoMART launch their new online shop!



OstoMART are pleased to announce that their new online store is now open for business. The new store will sell a wide range of products to cater for the Stoma and Continence market. Products available for purchase will include our new swimwear range, underwear, support wear, an extensive range of accessory products, disposable and washable bedding protection, travel bags and a wide range of pouch covers amongst other things. The store is user friendly and if you register your details then your account will remember your previously purchased items when you visit again, making the shopping experience easy and enjoyable.

To visit the website log onto www.ostomartstore.co.uk or telephone Freephone 0800 220 300 for a brochure.

Peak Medical

Peak Medical, UK distributor of the EuroTec range of ostomy products and accessories is pleased to announce the arrival of a New Range of Soft Convex 1-piece closed, drainable and urostomy pouches.

Designed with the wearer in mind, the integral, soft, flexible inserts provide the optimum depth and profile to manage most problematic stomas without the discomfort and rigidity associated with traditional convex barriers. Made from a traditional skin friendly 0.9mm thick hydrocolloid adhesive, the barrier is backed with a protective layer of SuperFlex stretchable foam for noticeable comfort and flexibility. For more information please see our advert on page 35 or call Freephone 0800 652 0424 and quote code M42 to receive your complimentary samples*.

*All convex products should be used upon the advice and guidance of a Stoma Care Nurse.

Also available from Peak Medical are the New Varimate Ultra Thin Hydrocolloid Retention Strips. Extra security and peace of mind when needed. Easy to apply, skin friendly, water resistant - ideal when swimming and bathing!

For more information simply call Freephone 0800 652 0424 and quote code M43 to receive your complimentary samples.
Now available on prescription from your GP and can be obtained from your usual supplier.

Visit Peak Medical's website: www.peakmedical.co.uk for more information.

Suportx Easy Peel Hernia/Abdominal Belts

Suportx have now launched a belt with a reinforced panel. This design allows us to increase the support level in a particular area of the device. This improves support for the wearer in the areas requiring support but keeps the other areas comfortable. The reinforced panel also allows for a hole to be cut out if required as it minimises the loss in support levels.

Bespoke service... We have found that many Ostomates with Hernias find it difficult to get good levels of support when using standard off the shelf products. Suportx are now offering a bespoke fitting service whereby we can arrange to either visit you or plan to see you in a clinic where you are expertly fitted for a support device. This is done in conjunction with your stoma care nurse or GP practise (if there is no nurse contact). The devices are made to measure and bespoke to individual requirements.

This service is open to all areas, for more information please call or Freephone 0800 9179584 or visit our website at www.suportx.co.uk

Vanilla Blush..offer

Vanilla Blush is delighted to announce that from the 1st August 2011 four of our wide selection of cutting-edge underwear will now be available on Drug Tariff:

- Two ranges for the women: feminine underwear with a twist of glamour;

- Two ranges for the men: reinforced underwear with a solid boxer style.

As with all our items, each product is designed to combine fashion and comfort – and covers all ages, needs and styles.

All the products have an internal pouch that runs from the left to the right and will not only support your appliance and stoma, will also provide you with confidence – that's underwear for the mind as well as the body.

Items will be readily available from all Delivery Companies.

For FURTHER INFORMATION please contact:- Annette, Aleena or Nicola on 01417630991/07988840286 info@vblush.com www.vblush.com

Readers Offer: Vanilla Blush is offering the readers of Tidings a 10% discount off all our sale products until the 31st of Aug 2012. Please contact us 0141 763 0991/07988840286 or info@vblush.com Quoting VBTMO

NB: Offer cannot be used in conjunction with any other offer.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Patient notes from Spain...

About two years ago, on a somewhat pleasant evening in June...I woke up with stitches from my bellybutton right around to the top of my bottom. I had just had an operation for bowel cancer in Hospital Santa Maria del Rosell, Cartagena, Spain.

The tumour had been 4 cm from my rectum and although I had an idea that a colostomy would be permanent, my surgeon had not explained about 'amputacion abdominoperineal', removal of the rectum. It was quite a shock although mitigated by the fact that I had read about the procedure on the Internet.

The next day, the nurses had me out of bed and into a chair for a few hours. Contrary to the urban myth, Spanish hospitals do a great job of patient care. They feed you, bath you, change your bandages and change your bag. When the bag gets full you press a button and a voice answers from a speaker in the wall. You then shout out what you need doing. When my Spanish was not understood, Antonio who shared the ward with me clarified my needs.

A nurse, usually male, emptied my bag and occasionally changed it. After a week, I was mobile and emptied it myself in the adjoining bathroom. The only stoma care nurse was on holiday and not due back until September, so I had no help or advice on colostomies or pouches. I left the hospital after two weeks with a 'goody bag' of Coloplast products. I came home with stitches in my bottom and feeling quite uncomfortable. The wound in my bottom had to heal from the inside out, a drainage gauze was left hanging out, which had to be changed daily and healing took place slowly.

Before we could set up an NHS nurse to visit, I organised help from the private sector. One nurse came from Almeria Angels and another, Madge, a retired nurse, came from a local urbanisation. Madge was great, she checked out my stoma, gave me advice and help on its management.

Jose, our translator, arranged recetas (prescriptions) for additional bags. Unfortunately, he got transparent ones, which did not appeal to me. I was also trying out two-piece bags.

A trip back to the hospital was agonising with my rear end stitches. When we arrived the nurses had departed for their mid-morning break. I was nearly in tears; Jose came to the rescue commandeering a bed trolley. No stoma care nurse yet, but I did get some advice and samples from the other nurses. The doctor who discharged me mentioned the possibility of 'irrigation', a procedure whereby you could go two or three days without changing pouches - it sounded interesting.

The following week, the 'district' nurse arrived. No, not the little white haired lady with the cap, blue uniform and black belt, but Antonio (another one) who wore jeans and a T-shirt, smoked and was 16 stone! He came every weekday. My wife Joan, had to collect the duty nurse on Saturdays from the Health Centre and on Sundays a fully equipped Cruz Roja ambulance arrived with three staff. They changed the dressings but were no help with the bag.

After six weeks the wound had healed and chemoterapia started. This was not the pre-operation chemo but six intravenous sessions followed by 14 days of large dose tablets. Up at 7.00 am to the hospital and queue for the blood test. After the test, it was off for breakfast and a wait until late morning for the oncologist. We chose a different café every visit and compared coffees and tostadas!

My oncologist, Doctora Edith would give the go ahead for the chemo anytime between 11.30 am and 1.00 pm, depending on when she finished her rounds. Then it was off to the 'lazyboy' chair for several hours while Xeloda dripped into my vein. Back home around 6.00 pm. Two weeks of tablets and a week off and by the end of that week I would begin to feel better, only for the next chemo session to start.

I had (finally) seen the stoma care nurse in Rosell Hospital who could not help me with irrigation, as she had no facilities (sink or toilet) in her room. I decided to wait until the end of the chemo before trying irrigation. I did contact Javi, a stoma care nurse from the charity 'Ayndate' in Murcia City. He drove 45 miles to visit me and showed me how to 'irrigate'- an absolute star.

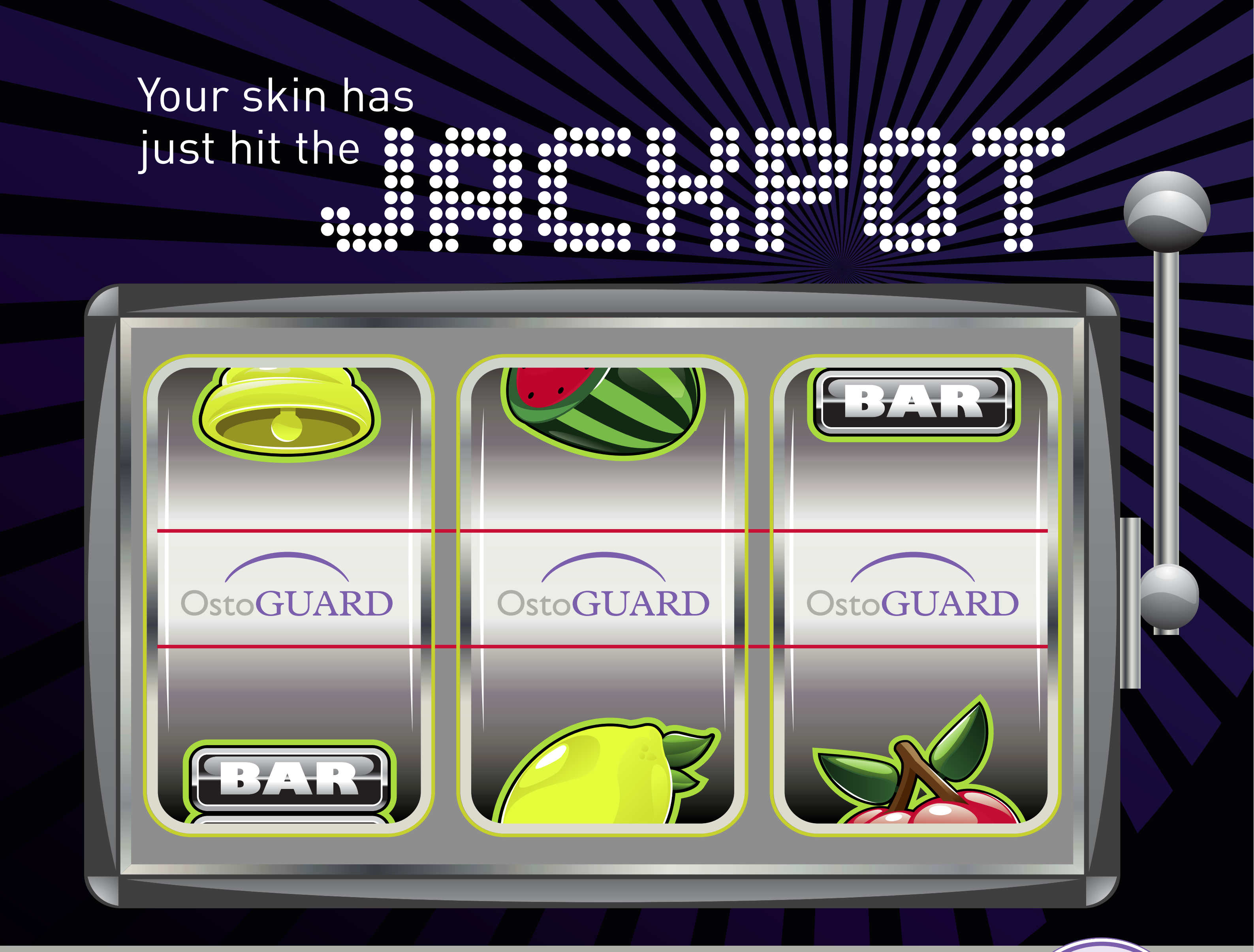
Chemo finished Christmas Eve 2010 and in January I started experimenting with irrigation. It worked pretty well on a daily basis and occasionally for longer. I settled for one-piece pouches for nights and times when menu del dias were being eaten. Coloplast Mini Caps were best for light summer clothes as they are less bulky. I used Conseal Plug for private moments and occasional visits to the beach.

In the late summer having mastered one-day irrigation with only a few mishaps, I was put in touch with Adrian March (www.stomadata.com) who lives in France and has been an ostomate for 15 years. He encouraged me to go for the two-day regime. I tried his method and generally it works. I now irrigate every two days around 6.00 or 7.00 pm. The evening session fits my lifestyle better.

I have been given the all clear (blood good - scan clear) by my surgeon. I don't have to see her for six months. I am reasonably free to continue my regular 4 km jogs; fortnightly 3 hour walks in the beautiful Murcia province and summer diving in the Med. I have even taken up golf again after a break of six years.

Am I happy? Most of the time. Am I sad? Sometimes. When my pouch inexplicably misbehaves, I sometimes get a little depressed, but usually not for more than a day. With a little careful planning, I lead a full life and look forward to more challenges in 2012!

Jon Thompson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"I actually feel like a different person when I clip on Vitala™"

"I wanted to enjoy my retirement. I've worked all my life and I was determined to have a wonderful time," explains Carole O'Ryan. Instead, the first five years were spent in and out of hospital, in pain and discomfort. Carole had long suffered from stomach problems, which led to a colostomy eight years ago.

Five months ago she started using the Vitala™ Continence Control Device (CCD) from ConvaTec, which has given her a much brighter outlook on her retirement.

"Unfortunately I have to live with a stoma so I have to find the most comfortable thing for me for day-to-day living," she explains. "Vitala™ has done that for me. It gives me control over my body," she says.

Carole admits: "I'm 65, I'm not going to get any younger! I'm going to go ahead and enjoy myself and try to put it all behind me!"

Loss of bowel control

Carole takes up her story: "I've always had stomach problems. I had to know where the toilets were because I had to go in a hurry all the time."

One dreadful day at work, without any warning, she had an 'accident'. She blamed a tummy bug, but two weeks later in the middle of the supermarket, it happened again. Carole was understandably shocked and worried. She was diagnosed with diverticulitis, inflammation of the intestine, but was determined to carry on as best as she could, working and going on holiday with her family as normal.

The breaking point came on holiday in Spain when she was rushed to a clinic, screaming in agony.

"I'd had enough!" she says. She was referred to a colorectal specialist and learnt that her loss of bowel control was down to her back passage losing its elasticity. It was irreparable and the surgeon suggested a colostomy.

Reluctantly, Carole knew it was the only way forward: "I was 57 and couldn't go on with my life the way it was."

More surgery

Unfortunately the operation was bigger than expected and life was not much improved. She had further complications with a parastomal hernia. "I lived with it, but a matter of months later I collapsed at home, with a strangulated hernia," she says.

Carole found herself back in hospital for an emergency operation and the stoma was re-sited on the other side.

"Since using Vitala™ I've got a very active life. I feel confident now"

"I had called my stoma George, so this was George the second," Carole says laughing.

But the first stoma would not heal and a hernia developed on the second. She recalls: "It was devastating – as big as a melon and terribly uncomfortable."

Nine months ago her stoma was re-sited back on the other side. "Yes," Carole says, "George the third!"

But her problems weren't over. Because her stoma goes in, she has to wear a convex skin barrier. "It wasn't sticking well so it was leaking. It was horrendous – I was still having accidents at night."

New device brings hope

Six months ago, Carole was at the end of her tether; nothing was working for her. That was when her stoma nurse told her about a new ostomy product, Vitala™ CCD. A month later, Carole was offered a trial. "It was completely different and I wasn't sure about it, but thought I'd give it a try," she says.

Carole says: "I started using Vitala™ and did exactly as I was told, building up the wear time from 2 hours to 4 hours. I couldn't wait till I could keep it on for the full 12 hours!" Vitala™ can be worn for up to 12 hours a day and then swapped for a pouch. It has to be supervised by a trained stoma nurse as it is not suitable for everyone.

"Once you start to know your stomach, you can work with it," says Carole. "If you use it sensibly, it's wonderful. Regaining control of my continence has given me a lot of my life back. It's given me a lot of freedom."

Carole says: "I actually feel like a different person when I clip on Vitala™. I come out of the bathroom and I'm walking more upright." She has found Vitala™ much kinder to her skin. The frequent bag and skin barrier changes and leaks that caused sore skin are a thing of the past.

Carole travelled a lot before she became ill, but over the last few years holidays were marred by her stomach problems. Now she is looking at holidays in a completely different light.

Her husband Danny retires this year so they are planning to go to Australia to visit his son. Three years ago he had to go alone because Carole couldn't bear the thought of the journey.

"Now I feel confident about travelling. I wouldn't even go on a train before. But with Vitala™ I'm happy to go to Australia for a couple of months!"

Carole has since started a stoma support group in Oswestry, Shropshire because throughout her illness and operations, she felt she would have benefited by speaking to others facing similar situations. She explains: "We meet monthly and talk about our problems over a cup of tea. There are 12 of us and everyone is encouraged to talk and moan! There's nothing to be ashamed of."

"Everyone has the same concerns. At first you don't want to talk about becoming an ostomate. You've got to come to terms with it yourself. But we've all found that if your family, friends and even workmates know what you're dealing with, they are more understanding," she says.

"Getting back to my normal life"

"With Vitala™, I've come further in these five months than in six years. I feel now I haven't got hospital looming over me. I was forever in contact with my stoma nurse or going back to the doctor's – it was soul destroying," she admits.

"Since using Vitala™ I've got a very active life. I've started doing wedding fairs with a friend. I don't feel uncomfortable or unsightly and I'm not worried about odour. I feel confident now," she says.

Please be advised that the testimonials above reflect only the experience of the user who has provided the testimonial. Results referred to in the testimonial may not be typical and individual results may vary.

For further information on Vitala™ Continence Control Device, please call 0800 467866, email vitala.webcare@convatec.com or visit www.vitala.com

VIT015
AP-012174-GB
February 2012

breakaway

putting smiles on young faces

Julie writes... Hannah, now aged 11 came home from school at the start of term, waving a letter excitedly in my face. "Mummy we're going away with the school for 2 nights and 3 days on an activity holiday!" OK…so I knew she would be fine with the activities as she has been on every Breakaway weekend since the beginning. Deep down I thought, "this is make or break time for you kid, this is your chance to show us you can manage on your own with two stomas, away from your comfort zone...home".

I had heard stories from Breakaway families, where parents haven't allowed their children to go on a school residential, for fear they wouldn't be able to cope. These children are striving to be like their peers, so to stop Hannah from going would have been the worst thing, as parents, we could have done!

Meetings were arranged with school, and we agreed that Hannah's teaching assistant would go as her named carer in case of any problems. Hannah decided she would like to sleep in a room with just her best friend, rather than a room of six girls, to allow her some privacy. Lists were written, bags were packed and...off she went!

As parents of a child who has been so dependant on us for the last 11 years, there was a massive lump in my throat...as off went the coach with Hannah and friends on board! I was so proud and a little lost!

After the trip, Hannah and her classmates arrived home full of stories...Hannah was 'buzzing' with "I DID it...I managed being away from home, Mum". But, as soon as I collected her from the coach, it was off to the October Breakaway weekend! Grandparents had offered to stay, so Hannah could have a night in her own bed, but, not a chance, she was adamant she was going to Breakaway! At Breakaway, Hannah proudly showed off her certificate and told everyone tales of what she had got up too!

What would I say to any parent facing this situation? Speak to your child's school...put plans in place, and let them go! It's the beginning of independent living and the confidence gained is immeasurable!

Julie Bastin
Founder and Trustee

Q&A's About Hannah's School Trip

Q: Where did you go?
A: We went to an activity centre in Shrewsbury last October!

Q: Was it cold?
A: Yes, it was very cold! I had about five layers on!

Q: What did you do whilst there?
A: We did lots of outdoor activities... a very long zip wire, canoeing (which was very cold), giant swing (very scary), archery (I was rubbish!), rifle shooting (I was rubbish at this also!). It was all great fun! I wasn't too scared as I'd done them all before at Breakaway!

Q: What time did you go to sleep?
A: Well, we had to go to bed at 9:30 but none of us went to sleep at that time! One group didn't go to sleep until 2:00 in the morning!

Q: Were you nervous about being away from home?

A: Yes, in a way because I wouldn't be with my mum and dad and...No because there was freedom from school, and mum and dad.

Q: Did you manage your Ace and Mitrofanoff without mum and dad?

A: Yes because I had a teaching assistant as my carer that went with me who knew what to do if anything went wrong - I knew I would be OK.

Q: Do your friends know you have an ACE and Mitrofanoff? If so did they help you?

A: Yes, my friends do know about my bits and bobs but some know better than others. I have one friend that knows in detail and she definitely helps me!

Q: Did you have fun?
A: Yes of course I had fun. It was amazing, awesome and brilliant!

Q: What would you say to anyone going away with their school who has a stoma and is a bit scared?
A: Well I would say it's OK to be a little scared because it's a new situation, but just go, don't let that get the better of you! Just enjoy being away! I did!

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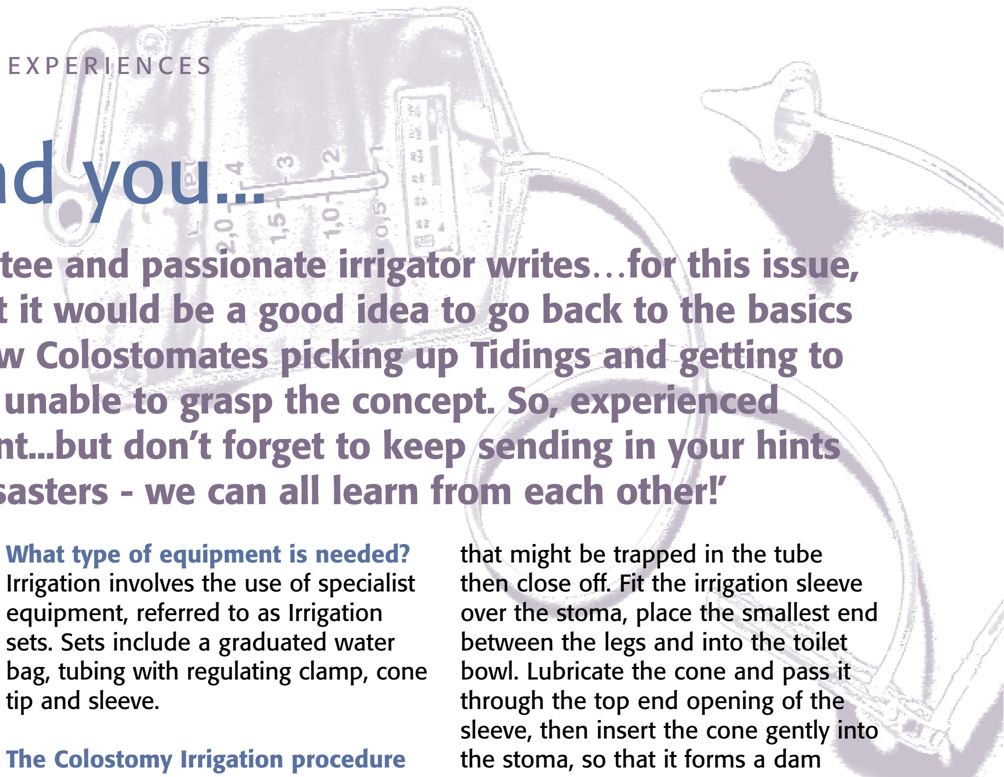

Irrigation and you...

Sue Hatton Executive Trustee and passionate irrigator writes…for this issue, the editorial team thought it would be a good idea to go back to the basics of 'Irrigation'...as many new Colostomates picking up Tidings and getting to the Irrigation article were unable to grasp the concept. So, experienced irrigators, please be patient...but don't forget to keep sending in your hints and tips - successes or disasters - we can all learn from each other!'

Sue writes... So with enough said it's back to basics...

Why opt for Colostomy Irrigation?

Irrigation can give the colostomate a new sense of freedom and control. In general, irrigation is a safe and effective method for achieving a continent bowel. It is not a technique, which suits everybody, although for colostomates who suffer persistent problems with their colostomy it may be an appropriate option. Patients suitable for irrigation are identified by their stoma care nurse. She/he will discuss irrigation to find out if the patient is happy to try it. If all is well the stoma care nurse will teach them the procedure which should adhered to at all times. Patients who are suitable for irrigation should have a left-sided colostomy either in the descending or sigmoid colon, with an output of formed faeces.

What is Colostomy Irrigation?

Colostomy Irrigation is used to manage faecal output by cleansing the bowel; irrigation does not wash out the entire bowel but clears the lower (distal) colon of faeces - this enables the bowel to perform the function normally performed by the rectum of storing faeces until they are evacuated.

Graduated water bag, tubing, water clamp, cone tip and sleeve

What type of equipment is needed?

Irrigation involves the use of specialist equipment, referred to as Irrigation sets. Sets include a graduated water bag, tubing with regulating clamp, cone tip and sleeve.

The Colostomy Irrigation procedure

A colostomate who regularly irrigates will gain an understanding of their body and overtime will identify the best time of day to irrigate - a time that suits them and fits in with their lifestyle. Organisation at the outset of the irrigation procedure is key to keeping relaxed and in control.

Gather together the items needed prior to irrigating:-

- irrigation set (see pic)
- tissues/wipes
- bowl of warm water
- 1 litre of tepid tap water (36-38°C)
- a non-sterile measuring jug
- stoma pouch or cap
- clothes peg
- disposal bag

To start the procedure make sure the environment e.g. bathroom/toilet is warm, comfortable and private. Layout your items and wash and dry your hands, ensure everything is within reach. Fill the jug with approx. 500ml tepid tap water 36-38°C (body temperature is 37°C) pour into the graduated water bag. The bag should be hung on a hook preferably behind the toilet bowl, with the base of the bag at shoulder height. When ready remove your clothing and position yourself on the toilet ready to irrigate.

Remove the used stoma pouch/cap and wipe away any excess faeces from the stoma and surrounding skin. Wash the stoma and skin carefully with warm water and gently pat dry.

Allow a little water through the tube via the clamp/flow control to expel air that might be trapped in the tube then close off. Fit the irrigation sleeve over the stoma, place the smallest end between the legs and into the toilet bowl. Lubricate the cone and pass it through the top end opening of the sleeve, then insert the cone gently into the stoma, so that it forms a dam between stoma and cone. Open the clamp/flow control to allow water to run slowly into the bowel (approx 8-15mins). Once the water has been instilled, remove the cone from the stoma, fold over the top of the sleeve and fasten securely with a peg. Wait for around 20mins muscular contractions (peristaltic motion) within the bowel cause the water and stools to flow out of the stoma into the irrigation sleeve then out into the toilet bowl. After the main flush, clean the lower end of the sleeve, fold up, and clip to the top end of the sleeve. After 10mins has passed and no further motion is felt remove the sleeve leaving it hanging over the toilet edge.

Wash the stoma and skin with warm water and gently pat dry. Apply a clean stoma pouch or cap. Clean the irrigation sleeve (if using a reusable one) by holding it over the toilet bowl pouring warm water from the jug into it or add a basin showerhead attachment to a nearby washbasin and use the spray. Hang the irrigation kit up to thoroughly drip dry then store in a cool place. Dispose of the rubbish as normal then wash and dry your hands.

Remember...says Sue... Everyone's body is different and that goes for the colon too! Your body will adapt to irrigation and you will learn what works best for you and your bowel. Many of us will still wear a one-piece stoma bag as we have a 'nervous tummy' and our bowels decide there is still a bit to go, when we think we have finished! Our motto is, 'Better to be safe than sorry!' There are those who can go for three days and only wear a stoma plug and

►


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an end colostomy, enjoy...
More
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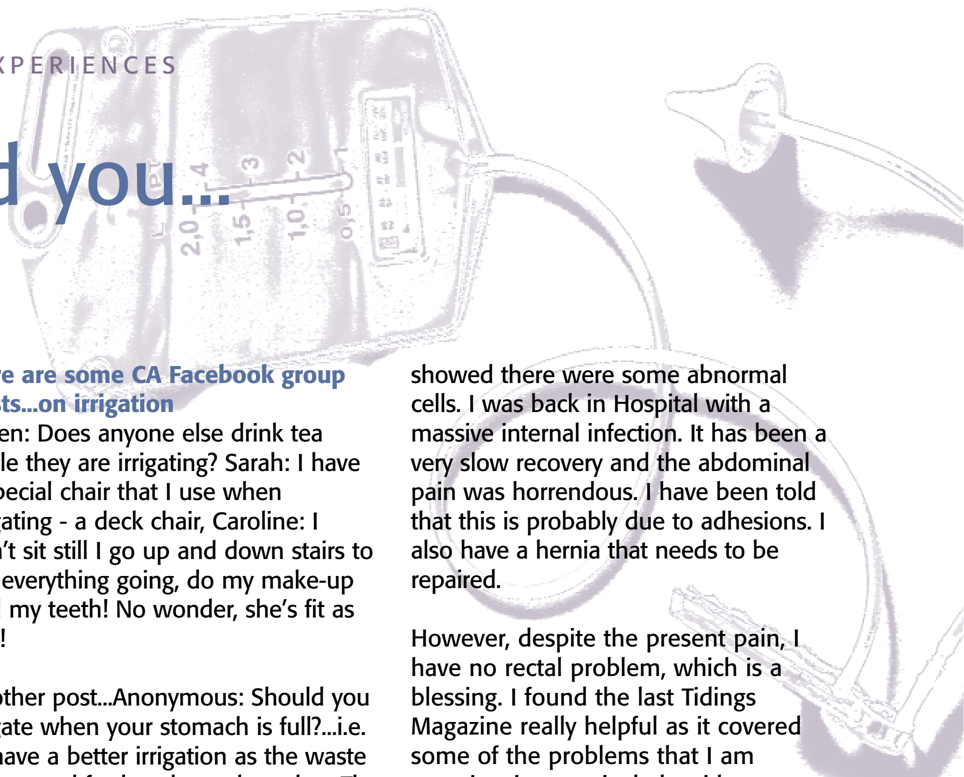
Irrigation and you…



there are colostomates who have given it a go, but prefer their own routine.

The great thing is, that provided you have enough large bowel and stoma is formed and an end colostomy and the cone can go into the stoma easily and water can flow into the bowel and that a stoma nurse is prepared to teach you...you can try it and if you don't like it, you can stop!

If you are interested in learning about irrigation visit our website: www.colostomy association.org.uk - just type 'irrigation' into the search pane and you will find lots more to read. YouTube also has some interesting video snapshots about colostomy irrigation again type 'irrigation' into the search pane. (It does look most peculiar, but I promise it's worth it!)

This letter proves that you are never too old to start irrigating...

Dear Editor,

I would like to thank Tidings for the articles on Irrigation.

I am 79 years old and had my stoma two years ago. Having been told I cannot have a reversal and reading your articles on Irrigation I thought, 'Why not me? There is nothing to loose, I can always go back to the bags', with the support of the wonderful stoma care nurses at Torbay Hospital - I am irrigating, it is three weeks now. I have 24hrs free of worry, wonderful!
I am very grateful.

Sincerely, OS

CA Facebook group...and Irrigation...

I find the CA Facebook group quite addictive and have to stop myself checking the 'posts'. Thank goodness for Duncan, Sarah and Helen...CA Facebook administrators they do such a great job! The site is so supportive – it's such a help to share your concerns or worries with someone else, it's a humbling experience.

Here are some CA Facebook group posts...on irrigation

Helen: Does anyone else drink tea while they are irrigating? Sarah: I have a special chair that I use when irrigating - a deck chair, Caroline: I don't sit still I go up and down stairs to get everything going, do my make-up and my teeth! No wonder, she's fit as flea!

Another post...Anonymous: Should you irrigate when your stomach is full?...i.e. to have a better irrigation as the waste has moved further down the colon. The reply from the group: we do it at the most relaxing time for us, at any time of the day or evening, before or after meals, it's whatever suits the individual.

However irrigating is not all plain sailing...as Kate writes:

I was born with Spina Bifida, a lipoma (benign tumour) developed within the spinal column. Although the tumour was removed twice it has re-grown and has tethered itself to the spinal cord and is no longer safely operable. I have little feeling in my left leg and virtually none in my right and all below waist functions are severely impaired.

For in excess of 20 years I have struggled with bowel problems and been unable to pass anything naturally and have had to manually evacuate, so you can imagine how pleased I was when my surgeon was persuaded to help, the prospect of going into old age with the possibility that I would have to rely on someone to perform this task for me was just not going to happen.

My GP persuaded my Colorectal Surgeon to do something.
He reluctantly, injected a similar product to Botox into the rectum, this made things worse, not only did it not lesson the rectal pain, but it left me unable to urinate properly. I was told this would right itself in time but it has not. Some time later, the Consultant, again, very reluctantly, through keyhole surgery, removed my rectal stump. However I woke to find the biggest keyhole imaginable. Problems I was told! However the rectal stump and the pain it caused had gone. I was told that the biopsy showed there were some abnormal cells. I was back in Hospital with a massive internal infection. It has been a very slow recovery and the abdominal pain was horrendous. I have been told that this is probably due to adhesions. I also have a hernia that needs to be repaired.

However, despite the present pain, I have no rectal problem, which is a blessing. I found the last Tidings Magazine really helpful as it covered some of the problems that I am experiencing, particularly with constipation, it had not occurred to me that adhesions might be a contributing factor.

I prefer to irrigate, but it is becoming increasingly difficult as most of the time the water just forcefully spits back at me (very annoying). On investigation I am sometimes unable to locate an open passage for the water to pass down, even gentle prodding with my finger will not open the colon. Sitting, standing, leaning on one side or tilting back or forward. 'Some days it just ain't going to happen' and I have to give up. On other occasions there may be no problem at this stage but I can't trust that the procedure is complete for a couple of hours later, just when I think it's all over, I find this is just not the case! Could it be that the adhesions are trapping the water? I am not usually so miserable. Sorry! Thank heavens for Oramorph.

Editors Comment

A leaflet - 'An Introduction to Irrigation' is available

telephone:
0118 939 1537

contact:
Colostomy Association
2 London Court East Street
Reading RG1 4QL

e-mail:
cass@colostomyassociation.org.uk

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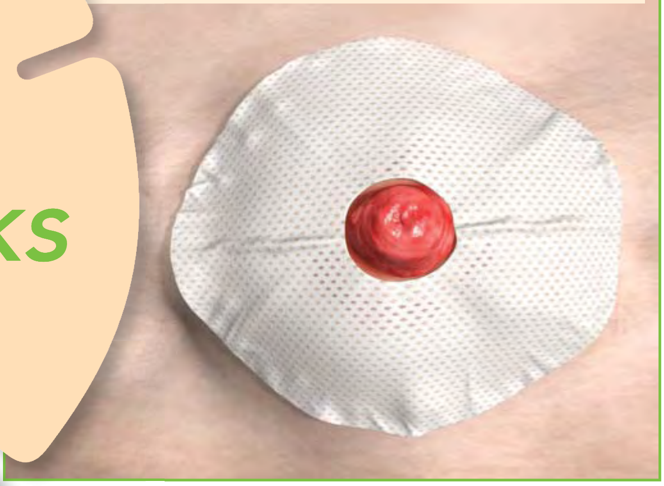
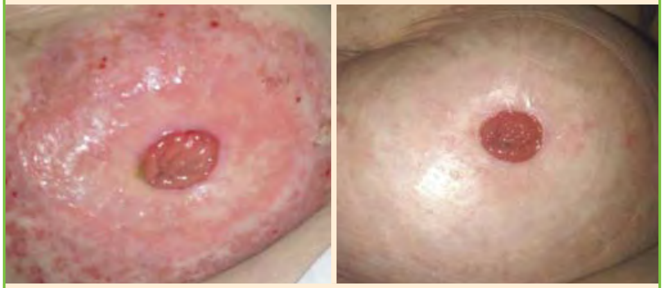
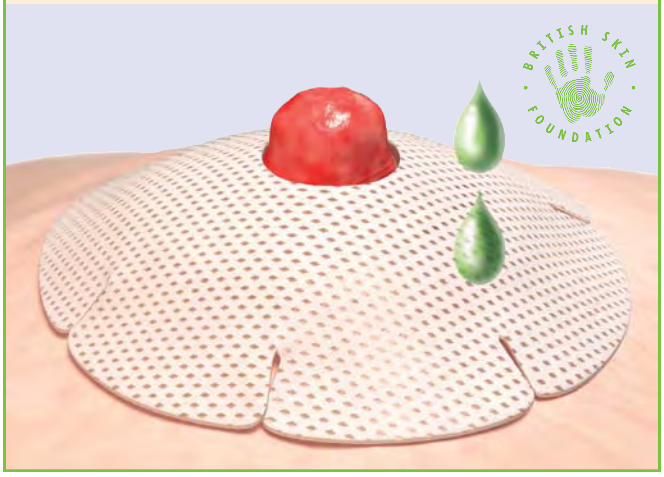


From this........... to this, in 8 weeks



After switching, this colostomist's skin healed within eight weeks and the wafer containing extracts of Aloe Vera helped to soothe her sore skin.



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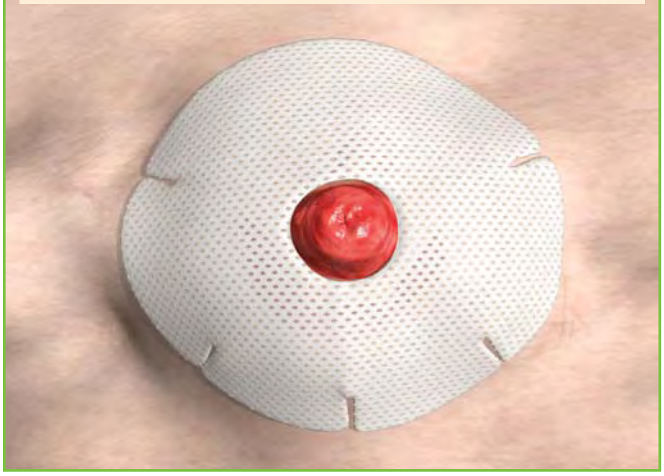

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A bag for life?

Sometimes life changing events of which we often have no control can place us on an unexpected path...in this article Michael Wood shares his patient journey and his invention... which came to him out of the blue...to ease the lives of ostomates

In 2006, I thought I had haemorrhoids and tried self-treatment to go with my self-diagnosis. Fortunately, I had the good sense to realise that I had better ask an expert too. My piles turned out to be a very large tumour a few inches inside the rectum. The tumour was too big for a local operation; the rectum had to be removed and I woke up with a colostomy bag, my first experience of being an Ostomate. I got used to the bag but could not help looking forward to the reversal operation to remove it. The challenging part of this period was not the bag but getting used to a different eating pattern and discovering what worked and what did not. Avocado with prawns worked really well!

Michael pictured with his wife Aselle celebrating Valentine's Day

Strange, but the reversal sticks in my mind as a truly painful experience during which I longed for old-fashioned gripe water. I eventually solved the wind pain problem by smoking my pipe in the local park. So, life and work back to normal… until late June 2010. I called Christopher Chan, my surgeon, and told him something weird was going on. He saw me quickly, took a biopsy and set an appointment for a few days later. I was not worried as my diagnosis was gallstones. With my diagnostic record, you may have guessed, my gallstones were, in fact, a particularly aggressive cancer of the colon. Christopher explained my options, somewhat limited due to the earlier operation, and I chose to have a full Ileostomy and removal of the anus. He operated within two weeks.

After close on a month in hospital (because of post-operative pneumonia), I was sent home to my wonderfully supportive wife and home cooking. The bag was like an old friend. You never forget how to ride a bike and, in my experience, the same is true of ostomy bags, their care and changing. More difficult, at first, was wearing nappies but, as the wound healed and I got what the Americans call a "Barbie butt", this problem faded into dim memory. Once healing had progressed, I had a course of chemotherapy, well, courses, actually. At first, the Hickman line was brilliant – until I suffered a large thrombosis in my left arm and it had to be removed. Then, I was prescribed tablets and, in short order, got spots all over and lost the skin from my soles and palms. It seems I have an overactive immune system that attacks just about everything – except cancer – and no one seems able to explain that conundrum. Finally, my Oncologist, Dr. Nick Plowman, put me on a combination of drugs much favoured in Japan and that worked. Now two check-ups after the end of chemotherapy, I am clear.

Despite having to inject myself every day for months with an anti-coagulant to deal with the thrombosis (it was a relief when that finished - I was running out of fresh places to stick the needle), food became a pleasure again in the sense that I discovered I could eat old favourites once more, curry, for example. One of my hobbies is cooking and experimenting is always fun especially when there is a direct result. I guess everyone is different but I have discovered that I can treat stomach upsets and looseness by eating very spicy food.

My bag is "for life" and thanks to the bag – I live! Apart from that, there are other benefits. As I cannot get colon cancer, I can eat steaks without a conscience, except I'm not very fond of them.

However good life is, there is, it seems, always something that's like a stone in one's shoe on a ramble. So it was with toilets they drove me mad! Public toilets, disabled ones, in hotels and restaurants, as well as those in some folk's homes. Where are the hooks to hang your clothes and bags? I wear braces (I tried wearing a belt but that blocked the stoma output, once with spectacular results in a West Country service station) and that means removing the layers that cover them, difficult especially in winter as one paddles about in the average loo.

Are other people content to put their things on the floor, or have they learned to make a bundle they balance on their heads?

Bin bags are amazing things, especially, the black variety. We lived for a while in North London; the bin men were choosy in the extreme over what they would take and there never seemed any logic or rule in their action. One day a neighbour told me, ‘Use a ‘black’ binbag, they always take those.’ They did. Being binbag friendly and aware of their multiple uses, I decided they could solve my toilet problem. To keep one’s clothes and bags clean while using a public toilet, put them in a binbag and bin the binbag after use. The only slight problem was fishing around for my clean stoma bag inside the binbag. Ever noticed how, when one doesn’t need it, things take on a life of their own and jump all over the place?

I decided there had to be a better way and, as with most things, an idea just popped into my head one day, seemingly out of the blue in much the same way that the answer to a crossword clue will, if ignored for a while. So, starting with my idea I created a prototype - a temporary hook system, Tidy Pal, a squashy ball attached to some heavy-duty tape onto which I sewed plastic hooks. Heath Robinson, I know, but it worked for me and solved my problem. “Can we have one too?” asked friends and acquaintances and, surprisingly for me, none of them were Ostomates, just people who don’t like getting their things dirty.

Although 69 at the time, I had no interest in retiring and Tidy Pal was in that sense a double saviour. Having worked in commerce and industry all my life and in many different countries, I had a good idea about manufacturing and discounted any idea of doing it myself due to the cost of setting up production in the UK. Amongst my contacts in China, Hong Ying Huang stood out as an exceptional manufacturer. This lady had driven me crazy at times with her attention to detail and insistence on quality but that is precisely what I needed for Tidy Pal. She agreed to produce the product for me and that started a nine-month journey of design development and patent applications that resulted in the first commercial product in late December 2011.

In March this year, I was 70. I know that I am lucky. Fortunate in having a great relationship with my wife whose stamina and incredible support is a source of constant amazement. Fortunate too in my family, friends and the medical team who treated me. All this has allowed me to fulfil a long held ambition – to start a business when most others are giving it up. OK, some may think that is perverse but it is an incredible amount of fun and whatever life now has in store for me, it’s a great way to start being a septuagenarian!

So, now having said that, I would like to introduce you all to Tidy Pal! My hope is that it will help you as much as it has helped me – in more ways than I can mention!

Michael Wood

About Tidy Pal...

Many disabled and public toilets have no hooks or clean places to keep one’s possessions. Ostomate, Michael Wood has invented an answer. Tidy Pal is a lightweight (140 g/5 oz) portable hook system. It will store a bag and handbag, umbrella, magazine, topcoat, jacket cardigan, etc., hygienically and safely. It fits any type of door and there is an attachment provided for use with room dividers. It is quick and simple to use and needs no tools or fixing. It can be used for temporary storage in offices and at home too. After use, it folds back into its own integral case.

How to obtain...Tidy Pal

Tidy Pal is available from
Tidy Pal Limited, Unit 35A,
Spaces Business Centre,
Ingate Place, London SW8 3NS
Tel: 07954318944.
Web: www.tidy-pal.com

Price: £14.75 inc. VAT and p&p

facebook
remember...everything is controllable...

Facebook at first glance may not seem easy to use...and has often attracted media hysteria...but Facebook is fast becoming one of the dominant communication platforms of our time... if you had any reservations about joining Facebook put them aside as Duncan Wells CA trustee discusses some of the intricacies of managing your CA Facebook account...

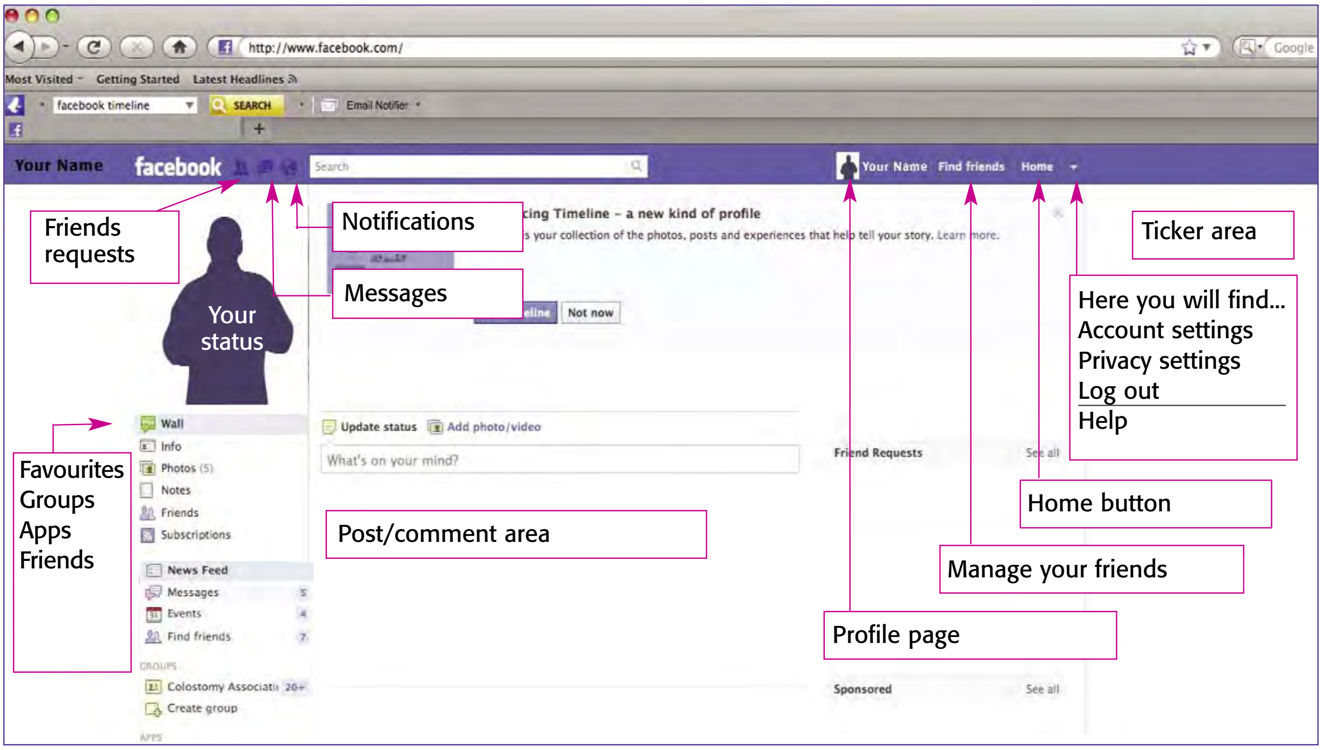
Setting the record straight, first and foremost you cannot have your identity cloned by joining Facebook but it is up to you to determine how much or little information about yourself you wish to provide.

It is up to individuals to take control and responsibility for their own identity on social networking sites such as Facebook, even if that means turning on the most strict privacy settings and sharing very little about themselves. For those willing to share more, being on social networking sites opens up a new ability to connect, interact and bond with people who have the same interests or have had similar experiences.

To sign up to Facebook (it's FREE by the way) the first step is to register for a new Facebook account. You will need four pieces of information: name, e-mail, gender and birth date (you can choose to hide this later).

You can chose an alias if you wish and you can select your age but make it over 13 otherwise you will be unable to post comments.

If you are interested in joining Facebook the diagram below shows a typical Facebook 'Wall'. The labelling indicates some of the key features. The Facebook site itself provides lots of helpful advice to get you started, so to learn more...visit: www.facebook.com/help/basics

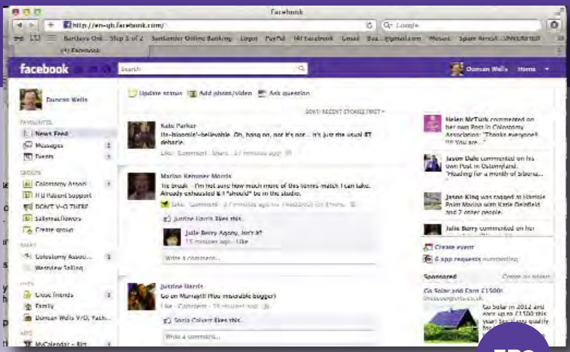


The above diagram indicates some of the key features found on a Facebook 'Wall'

So...let's assume you are now on Facebook - you have two pages. One is your Wall, this is what the public sees which looks like this FB1 (I am on Timeline, the latest version of FaceBook) and the other is your Home page also called a Newsfeed page which *only* you can see, which looks like this FB2.


FB1

Your Facebook Wall


FB2

Your Facebook Home page or Newsfeed

So now you can join the CA Facebook Group. **None** of the posts here will come up on your Wall - the public side of you. But posts for those people with whom you are friends will automatically come up on your Home/Newsfeed page. They will come up in a column on the right called the Ticker. The Ticker is a live rolling list of posts, comments and likes from your friends as they make them. Look at **FB2**, at the top of my Ticker list is a note that Helen McTurk has made a comment within the CA Facebook Group. If I put my cursor over Helen's announcement up comes her original post and all the subsequent comments **FB3.** Helen's new comment will be the bottom of all this. Now although this is the private part of my Facebook I may not want anyone looking over my shoulder at this. So let us say I don't want these notifications on my private Home/Newsfeed page. Notice that on the top right of the expanded Helen post is a greyed down arrow? It is greyed because I have placed the cursor over it. Click on it **FB4** and you get options to 'Report story or spam' or because you are a member of the Colostomy Association Facebook Group, 'Hide all from the Colostomy Association'. Click on this and Bob's your Auntie, you will not get any more notifications on your Home/Newsfeed page that your friends have posted in the CA Group.


FB3

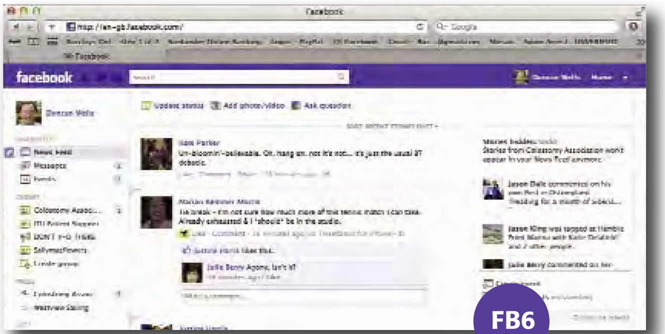
Helen's original post comes up


FB4

'Hide all from the Colostomy Association'


FB5

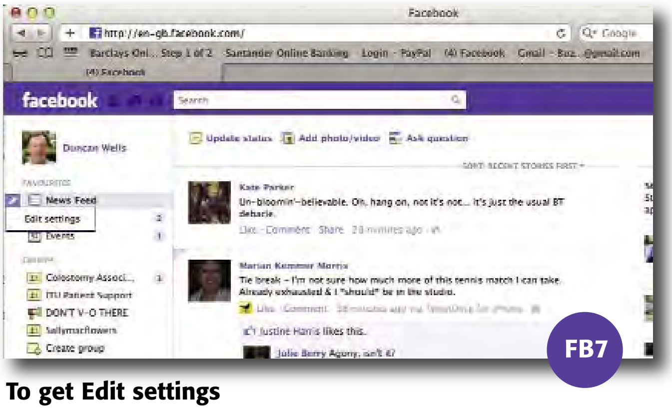
'Newsfeed' top is left greyed


FB6

Get the Edit pencil and click on this

Decided to change your mind and now want to receive these notifications on your Home/Newsfeed page? Then starting with your Home/Newsfeed page **FB5** you will see that 'Newsfeed' on the top left hand side is greyed. Hover the cursor next to it to get the Edit Pencil **FB6**, Click on this to get Edit Settings **FB7**. See overleaf...Page 32.

facebook
remember...everything is controllable...



Kate Parker
Un-bloomin'-believable. Oh, hang on, not it's not... it's just the usual BT debacle.

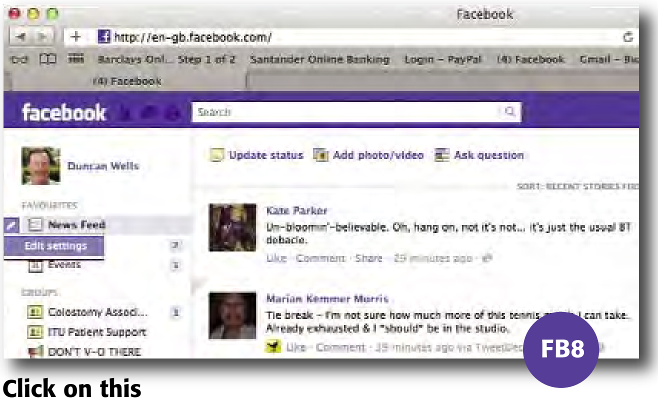
Marian Kemmer Morris
Tie break – I'm not sure how much more of this tennis match I can take. Already exhausted & I "should" be in the studio.

Justine Harris likes this.

Julie Berry Agony, isn't it?

FB7

To get Edit settings



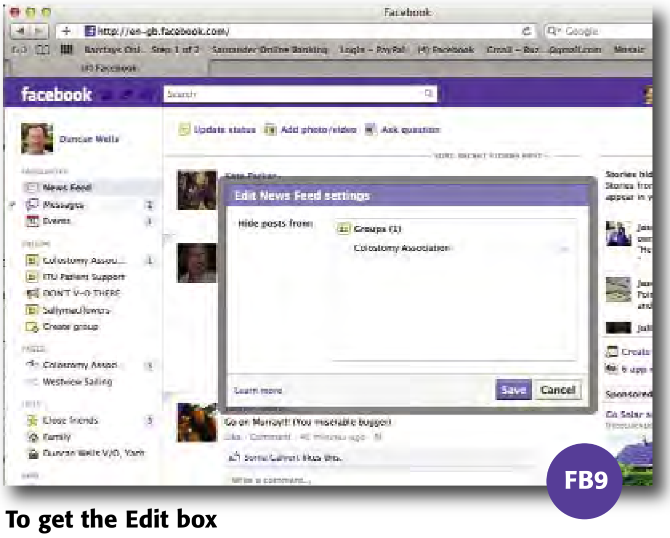
Kate Parker
Un-bloomin'-believable. Oh, hang on, not it's not... it's just the usual BT debacle.

Marian Kemmer Morris
Tie break – I'm not sure how much more of this tennis match I can take. Already exhausted & I "should" be in the studio.

FB8

Click on this

Click on this **FB8** to get the Edit Box **FB9** you will see it says Groups (1) Colostomy Association with an 'X' to the right on the same line. You have to remove the Colostomy Association from here by clicking on the 'X.' When you hover over the 'X' the word 'Remove' will come up **FB10.** Click on the 'X' and then click 'Save'. What you are doing is removing the Colostomy Association notifications from having been removed from your Home/Newsfeed notifications. In effect two negatives are making a positive, so you are adding the notifications to your Home/Newsfeed page. Remember a man - I use the term loosely - has made squillions of dollars with this sort of counter intuitive logic.

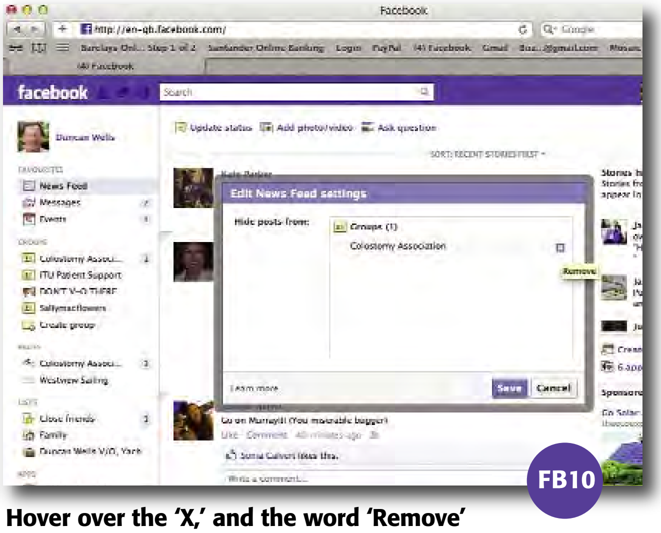


Go on Murray!! (You miserable bugger)

Sonia Calvert likes this.

FB9

To get the Edit box



Go on Murray!! (You miserable bugger)

Sonia Calvert likes this.

FB10

Hover over the 'X,' and the word 'Remove' comes up - click the 'X' to remove.

So that's how you stop the notifications and how you start them up again.

A few notes... Be careful who you befriend. Remember also that to become friends with someone, one of you has to ask the other and the other has to confirm. To unfriend someone you simply go to their Wall, click on the Friends button top right of their Wall and click unfriend. Or you could go to any post they have made, hover over their name and up comes a box which contains a Friends button, click on this and unfriend them from there. Apart from this there is a lot you can do to fine tune your notifications. For these you need to go to your Home/Newsfeed page and at the top right in the blue header bar is a down arrow icon, click on it, and a drop down menu will appear. Click on Account Settings then on the left hand side menu choose Notifications. And then take each area separately and choose what you want to edit. I have everything turned off except people who ask me to be friends and confirmations of friend requests and of course notification about CA Group member requests. That's it. You don't after all want thousands of emails telling you that such and such has just posted.

Remember, Facebook is ever evolving so the only way to keep up with it is to become involved and discover what a fabulous role it can and does play in helping others. To read more on the CA Facebook group go to Helen's story on Page 34.

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COLLECTION

The CA and Facebook

With the worldwide web and the gap between cities, countries and continents diminishing... we are now seemingly part of one local community...talking to each other on phones, on iPads, on laptops, PCs, face to face via Skype and of course via Facebook...CA volunteer and CA Facebook administrator – Helen McTurk gives us an insight into Facebook and the CA Group...

There are reported to be around 800 million active Facebook users around the globe. Companies, organisations and charities use it too. It provides a fabulous platform to present your organisation to the world. It's a great way to keep in touch with friends and colleagues and to inform any number of people in one message of important news. "Football has been cancelled today – kick off next Saturday at 10.00 am", posted on Facebook by the football organiser will immediately appear on the Facebook home page of all those needing to know. Facebook allows like-minded individuals with similar interests and passions to find each other online, to form groups and share information, advice, support and friendship.

So how does Facebook work?

Individuals have their Wall, which everyone can see, and their Home/News Feed page, which can only be seen, by the individual (as we have learned from Duncan – see page 30) and news about the individual or messages from friends appear on these. Companies and organisations use Facebook in a slightly different way; there is no public and private element to the news and information section. An organisation like the CA has a Facebook page which is public and is where the CA can post announcements and where others can comment. Here the CA can promote itself, link with industry events, post news of product innovation, raise funds and help to change the public perception of ostomates. This is also one of the places to learn about the CA Facebook Group.

The CA Page

At present the CA Page announces the new 'Donate to the CA' button and introduces the Facebook Group. But the minute there is a major event to promote you will see it announced here.

The CA Group

Our CA Facebook Group is a 'closed' Group, that is to say, one must join to see what is being written, it provides a community for ostomates to share experiences, information, and to help each other. It allows ostomates to connect personally and build friendships. It is like one large family.

"This group has changed my life! I spent 14 years in silence and now you can't shut me up! The people here are the most wonderful, amazing, brave and mad people ever! Never thought I would laugh so much either. I think of them with genuine affection and really don't know what I'd do without them. I'm not alone anymore."

The Group had been 'open' where anyone could read the posts but since we have become 'closed' there has been a noticeable difference. People who were worried to tell their story (because anyone could have read it) have now opened up and shared their experiences, being much freer about what they say, thereby strengthening the community.

"This is a fab - Facebook group! And now we are 'closed' I find that members are more outgoing in their posts, more personal in their comments and more willing to tell their stories"

Some people are real characters. We have one lady who needs to eat lots of sweets. No, seriously, she tells us that the doctors and nutritionists have told her she must eat sweets! She is a Malteser fanatic and sends in photos of enormous bags of Maltesers. Recently she was working in her greenhouse and sent a shot of the potting she had been doing with a big bag of Maltesers in the foreground, prompting the comment on her post, "You'll never get those to seed, duckie!"

So you can see that's what the Group's all about – sharing – experiences of living with a stoma, or in some cases two stomas! Helping each other, sharing the fear of a forthcoming MRI scan, or the misery of a failed operation or a new diagnosis of cancer, or the joy of an 'all clear', the ups and downs of daily life, gaining comfort and support from people who really understand.

The sharing of information about a new product, or something that works for you that someone else hasn't tried cannot be underestimated, improving of the ostomate's lot. The group talks

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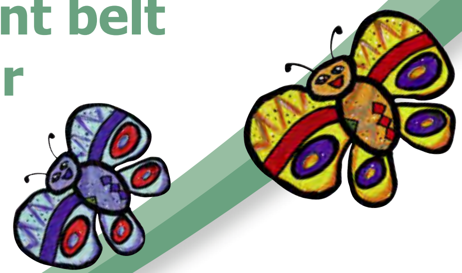

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about anything and everything from how to deal with sore and painful skin, to thoughts on how to tell a prospective new partner about your stoma. When one of our members was rushed into hospital, waiting late into the night, in pain and anxious about what would happen, we were able to post messages of support which she was able to read on her mobile phone in bed.

The group really comes into its own when someone new arrives, often in a fluster or sometimes in a terrible state with their newly acquired stoma. It is not uncommon for patients to fall between the cracks as they move from hospital to the community, they often find their way to the group in desperation. Within a few posts the current group members help them, by sorting out their worries and helping them find what they need. More importantly the new member realises they are not alone and this is the start of coming to terms with their stoma.

"Normal people – doing normal things – with abnormal circumstances. A great group to be part of."

Group meet

With our new family in mind and the fact that we know each other so well on the group, one member suggested that we all meet up. So, with the help of Salts Healthcare, around 25 of us will be doing just that. Salts Healthcare are kindly taking us on a tour of their factory in Birmingham in April and then hosting a meal in the evening.

Administrators

CA trustee Duncan Wells, fellow CA volunteer Sarah Squire and myself are the Facebook group administrators. We are there to maintain and uphold the reputation of the CA. We keep a watchful but friendly eye on what is being posted; just to make sure that everything runs smoothly. We have to remember that some people may be vulnerable or may find it difficult to adjust to living with their stoma.

Join us

You are very welcome to join our community; we like to think of it as a family. If you're on Facebook, you can type Colostomy Association in the Facebook search bar and then choose Group, or you can put this address into your browser http://www.facebook.com/groups/colostomyassociation2011/

If you are not on Facebook, why not join up – it's FREE. You won't have your privacy invaded and you won't be cloned, as you will know if you've read Duncan's article.

Helen McTurk
Volunteer and
CA Facebook Administrator

Hints and tips for new ostomates

When changing your colostomy bag

Use a peg to ensure your clothes are free of the stoma area. Try joining two pegs with a piece of cord long enough to hang round your neck and clip a peg on each side to secure and support your clothing in a more balanced way.

Standing upright while applying your clean bag will help to eliminate folds and creases and ensure a good seal on flattened skin.

It is not unusual for slight bleeding to occur where your bowel is stitched to the skin, so handle your stoma with care. However, if there is blood coming out from inside the stoma it is important to seek medical advice.

Try putting your new, clean flange/bag in a warm place e.g. on top of a radiator or under your arm for a few minutes to warm the adhesive which will help it to stick.

Some people find it easier to position their flange correctly if they stand in front of a mirror.

Stomas can change shape and size, especially in the first few months, so check weekly for any changes.

Many stomas are not round. Make sure that the flange fits as snugly as possible. If the hole is too big this can lead to sore skin. If it is too small the adhesive will be up against the side of the stoma and won't stick, allowing motion to collect behind the flange and cause leaks.

When measuring your stoma, use the backing paper of the flange as a pattern. Place it over your stoma then look in a mirror to check that it is the right size.

Gentlemen who have a problem with being hairy around the abdomen could try using a "Ladyshave". It gives a really smooth shave, is much safer than an ordinary razor and less clumsy than an electric shaver.

To protect the stoma while shaving cover it with the lid of an aerosol can.

A water-soluble antiseptic can be used after shaving to prevent a rash or skin irritation.

When showering with a colostomy bag still on, remember to cover the filter so it doesn't get wet and stop working. If you have problems drying the outside of the bag try using a hairdryer, but switch it to the lowest setting so there is no risk of melting the plastic or damaging the stoma.

If you have sensitive skin, before using a new type of appliance always patch test it on a small area - the other side of your tummy is best - in case of a reaction to the adhesive.

Changing your bag away from home

Don't forget your spare kit (stoma bag, wipes, scissors, disposal bags etc.) when you go out…and remember to renew it on a regular basis.

Many colostomates find it easier to change their bag in a wheelchair-accessible toilet where there is a wash basin and a bin for disposal on hand. See back page for details of how to obtain a RADAR key which opens locked toilets all around the UK.

When you know you will have to use public conveniences and there is no running water, take with you a very small "Body Shop" style spray bottle filled with water. Bacterial hand wash that does not require water is also useful. Some stoma appliance companies produce sachets of cleansing gel which are available on prescription.

Try flushing the toilet before you use it just to make sure that it is actually working. There is nothing worse than finding out too late that it doesn't flush at all!

Clothing

You will usually be able to wear the same clothes as you did before surgery.

Ladies who find wearing normal tights uncomfortable could try maternity ones. "Hold up" stockings are another option or "knee highs" if you are wearing a long skirt.

Wearing skimpy briefs which finish below the stoma or high-waisted pants that rest above the bag will prevent the waistband pressing on the stoma which may affect its functioning or lead to leakage.

Several companies make specialist underwear with an inside pocket which supports the stoma bag and keeps it away from the skin.

If the stoma is on the waistline gentleman may find using an elasticated belt or braces preferable to wearing a rigid belt.

High-waisted trousers may be more comfortable. Details of manufacturers and suppliers can be obtained from head office.

Patterned swimwear will camouflage any bulges.

Stoma bag covers, which will help to prevent your bag sticking to your skin in the heat, are available from some manufacturers.

Always wear a support garment when lifting heavy objects. Consult your stoma care nurse for advice on which type is most suitable for you.

Dealing with:

Odour

Most stoma appliances have a filter which incorporates a deodorizer, so odour shouldn't be a problem. However, if you are not happy with the filter on the bag you are currently using there are other bags made by different manufacturers that you could try.

Several manufacturers and suppliers of stoma care appliances produce drops or granules designed to neutralize any odour. These can be introduced into a clean bag before you put it on.

Odour could mean leakage or the filter may have come into contact with the contents of the bag making the deodorizer ineffective. If so change your appliance as soon as possible.

Some ostomates find that drinking tomato juice or buttermilk or eating natural yoghurt or parsley helps to control odour. Others take peppermint capsules.

Wind

Drinking peppermint tea or peppermint oil in hot water can help to reduce wind.

Eating fennel or drinking fennel tea is another remedy.

Pancaking

This is when the output collects around the stoma and sometimes squeezes between the flange and the skin instead of going into the bag. One of the reasons this happens is because there isn't enough air in the bag and so the output doesn't take a downwards turn.

Lubricating your bags with baby oil or one of the many products available from the various supply companies will help the motion to fall to the bottom of the bag. Squirt a little oil or gel into your bag and give it a good rub around before you stick it on. Take care not to get any on the adhesive as this can reduce the effectiveness of the seal.

Covering the filter with one of the sticky patches that are supplied in each box of stoma bags will prevent a vacuum forming inside the bag.

Leakage

Ask your stoma nurse about rings and washers which can help to give a really good seal around the stoma.

The growth of Fittleworth Medical Ltd

Fittleworth Medical Limited was founded in 1984 by Jaqueline and Alan Seymour from within their garage in the picturesque West Sussex village of Fittleworth. Right from the beginning, the Company was an innovator in the home delivery of stoma products. In the eighties, stoma flanges were not customised or cut to size before being sent out. Rather than leaving this to the customer, many of whom find using small, sharp scissors difficult, Jaqueline and Alan decided it would be a valuable and unique service to offer pre-cut pouches when necessary which helped launch the Company off to a flying start.

The Seymour's agreed from the outset – Fittleworth would be a company that really did put the needs of the customer above all else. Alan Seymour had been in the stoma care business for many years previously and saw a window of opportunity to help make Ostomists' lives easier by offering customers the choice to have 'made to measure' pre-cut pouches. Their strong, caring family values ran through into the business; a point of convergence was 'quality is everything' and their stringent attention to detail is what made them stand out amongst their competitors. Julia Constable, Managing Director of Fittleworth reminisces of the times Jaqueline and Alan would say, "What we do isn't difficult but it is so important that we get it right! Check the orders 3 times so nothing is incorrect, the customer is everything to us and we want to make sure everything is right for them." Julia believes "We owe them a lot of gratitude; they set deep solid foundations and high expectations which I strive to uphold."

The Fittleworth Customer Service Team, 2011

In addition to being one of the very first companies to manually pre-cut stoma pouches, the Seymour's also ensured Fittleworth deliveries were prompt, discreet and reliable. There was always a large stock available, and all appliances were supplied without bias to any manufacturer in particular. These founding principles remain true today.

By 1994 the Company had outgrown the Seymour's garage and moved to larger premises in Ford, West Sussex. A decade on from the first order the team had grown to include 30 staff. As the number of customers using the service was still relatively small, the staff needed to be multi skilled; taking orders over the phone, picking orders and manually cutting the pouches. All hands to the pump!

Over the following years Fittleworth continued to grow in size, in services, in strength and in knowledge. In 2009 Fittleworth celebrated its 25th anniversary. Julia Constable said at the time "This gives us a great opportunity to celebrate our origins and reflect on the enviable reputation we have built for reliable delivery and a discreet, confidential service over the years. I am extremely proud to say that after 25 years our core principles remain the same as when Fittleworth was founded. Our staff are just as determined and driven towards customer care as the original owners."

In 2011, Fittleworth opened a state-of the-art Care Centre in Rustington, West Sussex. This large 28,620 square foot flagship centre has been designed to cope with Fittleworth's future expansion plans. The Rustington Care Centre was built with no expense spared and due to the extensive, meticulous planning the project was delivered on time and on budget – a huge achievement for any business.

As Fittleworth continues to grow, focus is always kept on continuing to provide a personal, localised service. Fittleworth concentrate on local markets by having Care Centres located in major cities and towns throughout England, Scotland and Wales. Fittleworth also employs designated delivery drivers rather than using couriers for most customer

deliveries. Fittleworth has found employing their own team of drivers helps them gain greater knowledge of customer needs. Fittleworth understands customers prefer seeing the regular, friendly faces of their drivers who get to know the personal requirements. Drivers learn secret, secure places to leave the parcels if customers are out. They know convenient times to call on their regulars so they do not have to wait around. All Fittleworth drivers are CRB checked; only people with the highest compassionate, caring, and professional qualities become part of the team.

Steve Roberts, one of Fittleworth's drivers working in the South region, recalls the recent heavy winter. "Customers still required the delivery of their medical appliances but due to the snow many couriers were unable to leave their depots. Not us though!" says Steve. "We have our own areas and get to know a lot of the customers fairly well so we are not going to let them down. When the snow was really bad, I was loading my van with orders the night before, getting to work for 5.00am and getting home between 8.00pm and 9.00pm to make sure all my deliveries were made. I remember one day I drove out to a few houses that were at the top of quite a steep hill. Well there was no way I could get my van up there in the snow, so I parked it, picked out the orders I needed and started walking up to the top. One of the customers had been looking out for my headlights and was standing at the door waiting for me. He was so grateful that I had made it to him that he handed me a steaming mug of tea to warm me up for my walk back down."

Today Fittleworth delivers stoma, continence and wound care appliances. Fittleworth Care Centres range from Plymouth in the West to the Norwich in the East, and from as far North as Edinburgh right down to Rustington on the South Coast. Fittleworth's head office is located in Littlehampton, West Sussex only a few miles from where Fittleworth originally started. There are now over 200 employees including Care Centre staff, delivery drivers, nurses and territory managers out in the field, plus customer service teams who work on the phones and process prescriptions.

Louise Rutland, Consumer Product Manager says "Fittleworth still operates by the ethos upon which it was founded and we pride ourselves on offering a first class service. It is so important to us that our deliveries are prompt, discreet and reliable and customer service really does come first. One of our customers Mrs. J.M. rang our customer service line after 5.00pm on a Friday evening in a panic as she had run out of her medical appliances. Julia, our Managing Director found out where she lived and detoured to the customer's home to hand deliver Mrs. J.M's goods directly to her that night! This shows that if the Managing Director is happy to do this for our customers (and Julia says herself that she thoroughly enjoys making the deliveries) then these caring acts of goodwill will flow down through to the rest of the staff. Over half of the staff have made special trips to customers in need at some point in their careers. Fittleworth will always help a customer where we can!"

The World Assist Service

One service Fittleworth is extremely proud of is The World Assist Alliance scheme. Fittleworth were a founding member of this world wide scheme and are the only member in the UK. World Assist Alliance is a growing network of companies in many countries across the world; all dedicated to delivering medical appliances in an emergency to each other's customers. All Fittleworth customers have to do is contact Fittleworth who will arrange delivery from a local supplier within whichever country they find themselves needing products urgently. Whether they are in a hotel, on a cruise ship, in a tent or a villa, Fittleworth will endeavour to deliver emergency products as soon as is humanly possible. World Assist Alliance is completely free of charge, prescriptions are not needed, there is no paperwork required and there is nothing to claim back for insurance purposes. It's completely hassle free! Fittleworth currently have over 20 countries registered and the number is rising all the time.

Jackie Siney, Senior Customer Service Advisor recalls a phone call from a customer who was holidaying in Tunisia, "Mrs. C.G. had flown to Tunisia last November and it wasn't until she unpacked she realised she'd forgotten her pouches. She called our Customer Service Line and spoke to myself. I assured her we'd be able to arrange delivery to her hotel and spoke to one of our contacts in the area. Mrs. C.G. had a day trip booked between 2.00pm – 6.00pm and was soon to be moving on to another hotel so all parties had to work quickly and efficiently together. By the next morning the pouches were delivered and we had a very happy, relieved customer. It really gives our customers peace of mind."

Louise Rutland says, "Our success has been built on understanding the importance of each and every delivery. We appreciate that our customers have individual needs and make every effort to make life easier for them. This is reflected throughout the whole business - from our customer service team, our care centre staff and nurses, to our fleet of local delivery drivers who all understand the importance of treating our customers as individuals. This is supported by the fact that Fittleworth is not tied to any single manufacturer. Being impartial allows our customers and nurses to select the most suitable products for their needs. This makes Fittleworth one of the UK's leading specialists in home delivery services for Stoma, Continence and Wound Care products.

Fittleworths market leading service was endorsed by their recent win of the 'Stomawise Golden Owl Award 2011'. Fittleworth triumphed over several competing delivery companies to win the prestigious award which is made all the more special considering the votes are made by the customers. Louise Rutland explained, "this is the first time Fittleworth have asked their customers to nominate them and we were extremely proud and pleased to have won. Awards like this are what Fittleworth is all about, we exist to provide the best service we can for our customers and to hear that we are doing a good job is priceless."

"We often ask our customers how we can improve our service and always check that our customer's needs are being met, we would never become complacent and assume we are just doing a good job. We recently sent out 2500 surveys to our customers to ask what they thought of our service and how we can make any improvements. Amazingly we had 1124 replies; a 45% response rate. Of the respondents, 99.4% said they were satisfied or very satisfied with our service," says Louise.

Julia Constable said, "We are very lucky to be able to help as many people as we do. We are regularly told about this in the many thank-you letters we receive and phone calls we take. It is both humbling and inspiring and I would like to take this opportunity to thank all our customers for taking the time to express their gratitude, for the Christmas cards, the wonderful letters and emails, as well as the great feedback from phone conversations. Thank you - here's to the next 25 years and Fittleworth's continued success and expansion!"

For more information or to contact Fittleworth:

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Email: caring@fittleworth.com
Web: www.fittleworth.net

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TID-04/2012

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Readers' writes

Why not write or email the Editor of Tidings with your thoughts, experiences or hints and tips...

Dear Editor

I am a 77 year old active male. In reference to Mary Le Coyte's story on page 18 of issue 24 of Tidings, I have had a parastomal hernia for over two years. For the first year I tried many bags to avoid leaks with little success.

I have now discovered OakMed Options Microskin which are very flexible and fit a hernia well. I now get very occasional leaks. I also wear a SASH belt during the day and carry out quite heavy gardening etc. I feel it is important to have a good soak in the bath without the bag on every day and have had no skin problems at all.

R.S. (Mr)

Dear Editor

When I read Sue Hatton's comments about parastomal hernias in the Autumn 2011 issue of Tidings, I felt I was lucky. I have had a colostomy for over thirty years and I did not have a parastomal hernia until the last couple of years. It isn't particularly painful or even uncomfortable most of the time but it is truly unsightly. This winter I have had to buy tunic-type pullovers which are probably a size larger than I would normally wear but at least the parastomal hernia is sort of hidden. Not ideal but I cannot find a better solution. I would be most interested to know if someone has found a source of tops that conceal the hernia.

When I first showed my doctor the hernia she wasn't particularly concerned but as the months passed it was recommended that I have an appointment with the stoma care nurse to order a support garment. I didn't find it helpful that the stoma care nurse gave one look at the hernia and said, 'That's a whopper.' She recommended a belt and then later I was fitted with special support pants. However, both garments have the same effect of causing dreadful back ache.

Apart from the look I am not concerned about the hernia but am concerned that not wearing a support garment may make the situation worse. I go to Pilates twice a week and find the exercise particularly helpful for my leg which has lymphoedema (the lymph nodes were removed over thirty years ago).

I am delighted that more information about parastomal hernias is becoming available and that, along with irrigation, this topic is being brought to the attention of all colostomates reading Tiding.

Best wishes
S.W. (Mrs)

Dear ~~Father Christmas~~ Editor

Do you know what I'd like for Christmas?

A drainable bag but with a Velcro® opening at the top as well so that I can sluice it down with a little water, seal both ends again and feel clean! No more fiddling about with loo paper and lollipop sticks. And no more feeling guilty if I change my perfectly usable bag after a day just so that I can feel fresh.

I hope you're reading this Santa!
H.C. (Mrs)

P.S. I've given you till Christmas to start working on it.

Dear Editor

I have two stomas: Colostomy 1984 Urostomy 1990. I have a condition called Neurofibromatosis and I have also had two strokes. I'm still looking after the stomas myself but get in a mess some times.

I have two carers and district nurses come twice a week. Carers have no idea about stomas. I could ask the district nurse to help but I know I'm supposed to do it myself. I'm eighty years old now and find it hard as I don't see very well. My doctor says I use too many bags.

I enjoy Tidings and find it very helpful. Thank you for a great paper.

B.T.(Mrs)

Dear Editor

In the most recent edition of Tidings was a query regarding fully inflated bags. Sophie Medlin gave advice on diet to reduce wind. We are all going to produce some wind. I have found that the efficiency of the filters on different makes of bags varies enormously.

I would advise people to try different bags; they can ask for samples. For instance, I have no ballooning problems with Coloplast bags with first-rate filters (two, which makes adjustment easy), whereas another make of bag will inflate very quickly - and stay so. Experience shows my diet and body are not relevant here: it is the bags.

Different bags have different features so you may have to balance the filtering against the strength of the seal. Also, this lady has a new stoma: does she know about the filters and

Readers' writes

filter covers? I was never told by my stoma nurse: I found out from the suppliers quite a time later.

Best wishes
L.C. (Ms)

Dear Editor

I was born in 1927 when "regularity" was considered all important. I was told I had a "lazy bowel" and made to 'sit there till you produce a motion'. This could be hours and I suffered many attempts to force things such as massive enemas and soap sticks. As a result my rectal sphincter ceased to function and for years I relied on laxatives and constipating drugs. Doctors tried different methods and then a length of bowel was removed which made things much worse. In 2007 my colostomy was formed. Generally this has made things easier to manage.

I am battling with other problems at present: losing my sight through Macular Disease and with crooked fingers due to Arthritis. Reading the magazine one finds there are so many problems and different stories. Life deals us all differently. Sometimes it is hard not to give in to depression and say "why me?" But there are always others coping and I try to see each time something goes wrong as a challenge to find the most practical way of getting over it.

My tip for coping with a stoma when you have awkward fingers and failing sight is just do not try to hurry. I find it easier if I am completely naked when changing the bag and I remove all clothing which could get in the way before draining which has to be done frequently at the moment. I keep trying different ways but have rules for myself and "triggers" to remind me. The most important rule is: think ahead and make sure the next job is organised before you start. Thank goodness for all the wonderful stoma nurses. My experience has been that they are so understanding and a fund of knowledge and good advice.

With best wishes
P.M.N. (Ms)

From Rosemary...
Tidings Magazine can be 'Read Out Loud' via Adobe Reader...here's how

Read Out Loud is a Text-to-Speech feature built into Adobe Reader version 6.0 and higher. The Read Out Loud feature allows files with the extension .PDF (Portable Document Format) to be read out loud by a computer generated voice built into your computer's operating system.

Tidings magazine is available as a PDF file for download to your computer from the Colostomy Association website: www.colostomyassociation.org.uk

To use the Read Out Loud feature you will need to open the PDF first with Acrobat Reader - version 6.0 or higher. (The latest version of Adobe Reader can be downloaded FREE from http://get.adobe.com/reader/ for PC or Mac).

With Acrobat Reader open the Read Out Loud feature can be found at the bottom of the second main menu tab entitled - view. Click on 'Read Out Loud' a number of commands are available to you...

- Activate read out loud
- Read this page only
- Read to the end of the document
- Pause
- Stop

Click on the most appropriate e.g. Read to the end of the document – this will activate the speech engine and your computer's voice will speak the contents of the PDF out loud.

We would be interested to hear from other ostomates who have impaired vision or who have restricted movement in their fingers. If you have any hints or tips for managing a stoma do write in and tell us about them.

Dear Associate Editor

May I add my suggestion to the correspondence on dealing with contents and disposal of pouches. For some years I emptied the contents of my pouch down the toilet, after cutting off the top or bottom of the pouch with scissors. If the contents were sticking to the sides of the pouch, I used a jug of water to clean it.

However, a couple of years ago we upgraded our shower room and I had a douche installed next to the toilet. This gives a jet of water which easily cleans the pouch, which can then be sealed in a plastic bag and disposed of in our black bin. I have now started to irrigate and the douche can be used to clean the inside of the sleeve before disposal.

Yours sincerely
C.H. (Mrs)

Dear Editor

I was interested to read the article by Duncan Wells in the latest Tidings.

How I agree with him about the lack of coat hangers, not only in disabled toilets but also in normal ones. Also the small wash basins with no plug.

Readers' writes

I am usually able to hang my coat(s) on the raiseable arm of the toilet and find room to lay out my changing equipment on a hopefully flat cistern.

In the disabled toilets at the Peterborough Exhibition Centre there are nappy changing tables which I find very useful.

Yours sincerely
J.S. (Mr)

Dear Associate Editor

When I had my colostomy in 1992, I also followed most of the directions my stoma nurse gave me with regard to the disposal of used appliances. However, right from the beginning I knew that there were a couple of her suggestions that I would never follow, namely, cutting along the bottom of the full pouch with scissors as a means of emptying the contents, and rinsing the appliance out under the pressure of water produced by the flush of the toilet. Nineteen years later I still cannot see how using scissors and rinsing appliances in this way can be done hygienically.

Take the question of washing the scissors – where are you supposed to do this? In the washbasin, perhaps? It can't be good practice to allow faecal matter to come into contact with a basin which other people are then going to wash in.

As for rinsing out used appliances under the flush of the toilet, again I think that this is likely to cause more mess than it saves. I have always used the same method of disposal as Mr. A.B., which is to empty the contents via the hole it came in through, then fold the flange over on itself, which then seals it. I understand the theory behind rinsing out appliances before disposal, but I find that in practice it doesn't really work. If the contents are formed then there will be relatively little residue, in which case rinsing under the flush will only provide minimal improvement. However, if the contents are liquid, or thick and unformed, it is going to take a considerable amount of rinsing to bring about much improvement, and the process itself may even spread germs as the force of the flush on the dirty appliance is likely to produce unintended spatter. Realistically there is little benefit in rinsing a used appliance as germs will still continue to breed in it after disposal, and the process of rinsing dirty appliances may actually spread contamination.

Yours sincerely
B.B. (Mrs)

Dear Editor

I read with interest the article by Duncan Wells in the last issue of Tidings.

I completely agree with the comments that he makes regarding the lack of facilities, also about the freedom with which Radar Keys are issued. What check is made when you apply for a key? As long as you pay your money you can get one.

I also would confirm that I myself have suffered abusiveness on using a disabled toilet. So what I do now is when I have finished in the toilet I get my council-issued disabled card (size of a credit card) palm it in my hand so if there is anyone waiting outside to question my use of the toilet I just flash the card in their face. I then enjoy their look of astonishment.

B.H. (Mr)

Before acting on suggestions from other ostomates you are advised to check with a doctor or stoma care nurse that this course of action is suitable for you.

Thank you for your letters and e-mails. Please keep them coming. We will do our best to print them or we may hold them over for a future issue.

Editing may be required for reasons of clarity or space. In the interests of confidentiality we will publish only your initials and not your full name, unless you give us permission to do so.

If you want to be involved in the next issue of Tidings magazine **simply drop us a line**

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Look out for our Readers' Button to see where readers have contributed to Tidings

Readers' PANEL contributor


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Essentials
Handle with care
Appeel
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Medical
Adhesive
Remover
REF 3500
REF 3505
Appeel
NO STING
Medical adhesive remover

Dear Nurse

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

Q: *I had my colostomy last year in May, as a result of Diverticulitis which formed an abscess and perforated my bowel. After emergency surgery, I found myself on a High Dependency Unit (HDU). It was a scary moment. After nine months I am still having trouble coming to terms with my situation. I can change my bags because I have to but feel I am not totally accepting of my stoma. I am considering irrigation but after reading the information which was sent to me by my stoma care nurse, I am still not sure what to do for the best as I still get the odd flare up of Irritable Bowel Syndrome (IBS). Any information you could offer would be most welcome. Is there anyone out there who has been through a similar situation?*

A: There are many people you can talk to who have had similar problems and experiences to yourself. If you contact your own stoma care nurse she may have a patient she could arrange for you to meet.

Alternatively the Colostomy Association has trained volunteers who are colostomates that would be very willing to talk to you over the telephone if that is easier. The CA helpline is available 24/7, 365 days a year - 0800 328 4257. You could also ask your GP about counselling if you feel that would help you come to terms with your experience.

It can sometimes be very difficult to accept an emergency formation of a stoma as you did not have the chance to receive counselling prior to surgery but with help and support you will be able to adjust and lead a normal active lifestyle.

Julie Rust became Tidings Nurse in December 2004. She has answered readers' letters and e-mails in every issue which has been published since then. We look forward to many more years of publishing her very sound advice.

Your medical questions about stoma care management are always welcome and important to us.

Questions received by the Editor or CA are passed to Julie Rust RGN. Dip, N. MSc. CNS Stoma Care to review and answer. Answers are published in the next issue of Tidings.

I presume you have an end colostomy as you have been considered for irrigation. If you have IBS you may find that this flares up more with irrigation but there are other products, including closed pouches and Conseal plugs, which may be an option for you to try. I would suggest a visit to see your local stoma care nurse to see if she/he can help with any of these.

Q: *I had my colostomy due to bowel cancer in 1988 and a second operation in 2010. I have had several hernia repairs and my stoma has been resited but I have since had yet another hernia. I can't have any more surgery due to a heart condition. Could you please tell me if there are any other developments around hernia support that could make a difference to me? Thank you.*

A: Parastomal hernias are distressing to the individual and by the sounds of it you have had many surgical procedures to try to resolve this. There are different surgical procedures to help repair parastomal hernias but you say you cannot be considered for further surgery due to a heart condition.

Another option is to see if an abdominal hernia support can help. This is a made-to-measure support garment that you wear to help provide extra support on the outside to assist your abdominal muscles to hold the abdomen flat. I do not know what the referral system is in your local hospital but a review by your stoma care nurse would be able to give you more details and possibly arrange for a fitting to be done.

Q: *I have had my colostomy quite recently. I am worried about the skin around my stoma. It doesn't look the same at it did before and it's rather red. Can you tell me what I can do to change its appearance and is there a procedure that I am not adhering to? I would really appreciate some guidance.*

A: Skin around the stoma can become sore due to leakage of stool onto the skin, an allergy to an adhesive or an ill fitting pouch. Some people find the act of removing the pouch can traumatise the surrounding skin and the use of an adhesive remover wipe or spray can help this. It is essential that the skin around the stoma is kept very clean and that perfumed soaps are not used in this area, as they may cause irritation. A good fitting appliance is needed; to ensure that no stool gets onto the surrounding skin and for this reason it may be worth getting a review of the template by your stoma care nurse. If the problem is thought to be due to an allergy there are many different products on the market to use, including skin protectors and various manufacturers' pouches with different adhesive qualities.

Q: *My mother is 89 years old and has a stoma situated near her belly-button. It makes life very difficult as it dips in and her bag doesn't always fit properly. She has had a lot of problems lately with faeces not going into the bag but collecting around the stoma and then coming out at the side of her bag. My mother gets so distressed by it. Can you give any advice to prevent this from happening? Your help would be so appreciated. Here's hoping!*

A: This appears to be due to a very common problem called 'pancaking', where the motion sits at the top of the pouch and does not drop into the bottom. This is often due to no air being in the pouch or due to the consistency of the stool; if it is very soft and 'sticky' this will happen. Your mother could try keeping a food diary to see if this is related to any particular type of food and then alter her diet slightly.

Alternatively your mother could try some of the common solutions for 'pancaking', including using the small filter covers which you will find in the box of pouches, to cover the filters on the pouch. This allows air to remain in the pouch allowing the stool room to drop down. Gel can also be used; Adapt Gel from Hollister is one, simply put it into the pouch to lubricate - this will allow the stool to slide down. Or using a small amount of toilet paper rolled into a ball and placed in the pouch can help prevent the two sides of the pouch sticking together. A foam stoma bridge, available from Opus Healthcare, will do the same thing.

You do not say if the problem with the leaks has caused any skin soreness, but if it has your mother may wish to try a protective spray such as Cavilon. It may also be worth getting a review of the template to ensure it is a good fit, your local Stoma Care Nurse can do this.

Q: *My husband had a colostomy two years ago and is managing well. However he has a continuous infection from a fistula which is leaking from the colon into his bladder and vice versa. In an effort to deal with the problem he now has a catheter, which is causing him a lot of problems – one of the worst is an increase in the amount of mucous from his back passage which necessitates an urgent need to get to the loo. The catheter is very recent and he is also suffering severe pain to his penis. The mucous is a continuing problem. Have you any suggestions why the mucous has increased and can something be done about it?*

A: The catheter may be causing some irritation and if he has severe pain in the penis I would ask the District Nurse (who should be visiting to support the catheter care) to have a look to see if there is anything obvious causing the problem. Mucous from the rectum is a difficult thing to manage and can be very stressful. Often people need to wear pads to protect their underwear and give them some confidence. It is also important to care for the skin around the back passage to prevent it from getting sore and painful. I don't know what the long term plan is to manage the fistula in the bowel but your husband could discuss this with his surgeon at his next clinic visit.

Q: *I am 88 years of age and had my colostomy a few years ago. I care for my elderly husband who has Alzheimer's and cope quite well. Every six weeks or so I have a major problem, first, constipation followed by chronic diarrhoea. My bag explodes and I end up with a mess everywhere. Any suggestions?*

A: I would suggest a review by your stoma care nurse locally who can examine you and give you a better idea of why this could be happening. It could be diet related, due to stress or a change in medication or even due to a parastomal hernia. Without a more detailed conversation and examination I am unable to explain why this is happening, especially on such a regular basis but hope this has helped.

What kind of stoma do you have?

When food leaves the stomach it enters the small intestine, a long coil tube about twenty feet long. The last part of the small intestine is called the ileum. If the ileum is brought out through the abdomen to form a stoma (ostomy), this is called an **ileostomy.**

Five facts about an ileostomy

- The name comes from combining the words ileum and ostomy.
- It allows faeces to leave the body without passing through the large intestine (colon).
- It is usually on the right hand side.
- The output tends to be fairly liquid – the consistency of porridge or thick soup.
- A drainable bag is used and emptied four or five times a day.

Normally digested food passes from the small intestine directly into the large intestine or colon. If the colon is brought out through the abdomen to form a stoma (ostomy) this is called a colostomy.

Five facts about a colostomy

- The name comes from combining the words colon and ostomy.
- It allows faeces to leave the body without passing through the anus.
- It is usually on the left hand side.
- The output tends to be formed and firm.
- A closed bag is used and changed about twice a day.

The above applies in most cases, but there can be exceptions For example, sometimes it may be easier for a surgeon to create a colostomy on the left hand side. The output from some colostomies may be fairly liquid particularly if only a small amount of colon remains. Therefore some colostomates may prefer to use a drainable bag.

Editors Comment

Have you got a medical question or a query about stoma care management for Julie?

If so write in and tell us:

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

or e-mail your query to:
cass@colostomyassociation.org.uk
editor@colostomyassociation.org.uk

An **appreciation** of the **commitment** made to the **Colostomy Association** and a **celebration of the voluntary work achieved by...**

Stephen Bonham

It is with great sadness that we report the passing of Stephen Bonham, one of our most valued volunteers. Stephen was an especially gifted man and communicator, he listened to peoples problems, provided help and support and promoted the positives of living with a colostomy.

Stephen retired from his job in 1998 and applied to become a volunteer having received his colostomy in 1990. He was a very dedicated and extremely reliable volunteer, delighting in representing the Colostomy Association at Patient Open Days. Indeed, at our five year birthday celebrations...CA Patient Open Day at Gaydon, Warwickshire in 2010, Stephen along with Janet Bradley another dedicated CA volunteer manned a stand specifically set up to encourage and inform visitors of the benefits of Colostomy Irrigation.

Together they made an impressive team and were inundated with enquiries - from both new and experienced colostomates, spending a very busy day explaining this alternative method of colostomy management.

The Colostomy Association values every one of its volunteers, knowing how much time and effort they commit to raising awareness of the CA and advancing a clearer understanding of 'living with a colostomy'. Stephen was a volunteer who keenly went the extra mile dedicating his time and energy to both.

Very intuitive, Stephen understood people's fears and concerns, answering them in a kind and compassionate manner. He made such a difference to so many lives and we know that those he helped felt they had made a good friend.

In his working life Stephen was a principal officer in the Prison Service, a lifetime officer of the Salvation Army and later a much valued Colostomy Association volunteer.

He was kind, thoughtful and selfless, giving 100% commitment to those who needed him. We are especially grateful that he chose to share his abilities with the Colostomy Association using them to their full extent in his work as a volunteer.

Stephen worked very closely with Joan West, another volunteer who has also sadly passed away. Both Stephen and Joan worked hard to raise the profile of the Colostomy Association by promoting the Association whenever and wherever they could.

At the celebration of his life, held at The Salvation Army, Rugby on Friday 25th November 2011, tributes were read out and everyone who attended realised just what gifts Stephen has given to those around him - care, love and kindness.

'The miracle, or the power, that elevates the few is to be found in their industry, application, and perseverance under the promptings of a brave, determined spirit'.
– Mark Twain

We are all saddened by Stephen's passing and send our condolences to his wife and family. We are so proud of Stephen's achievements as a CA volunteer and he will never be forgotten – his legacy – caring deeply about others – is supported by the Colostomy Association. We continue through the work of our volunteers to provide help, support and reassurance to those 'Living with a Colostomy'.

Stephen, you will be greatly missed.

Helpful Ostomy Support Groups & Organisations...

- IA The Ileostomy and Internal Pouch Support Group
  Freephone: 0800 0184 724
  www.iasupport.org
- UA Urostomy Association
  Tel: 01889 563191
  www.urostomyassociation.org.uk
- IOA International Ostomy Association
  www.ostomyinternational.org
- Gay Ostomates
  Email: brian@gayostomates.org
  www.gayostomates.org
- Stomadata & Stomafr
  www.stomadata.com
  www.stoma.fr
- Macmillan Cancer Support
  Tel: 0808 808 00 00
  Mon - Fri: 9am - 8pm
  www.macmillan.org.uk
- Crohn's and Colitis UK
  Tel: 0845 130 2233
  www.nacc.org.uk
- The Gut Trust
  (Irritable bowel syndrome)
  Tel: 0114 272 3253
  www.theguttrust.org
- Bladder and Bowel Foundation (B&BF)
  Formerly Incontact and Continence Foundation
  General enquiries: 01536 533255
  Web:
  www.bladderandbowelfoundation.org
- Bowel Cancer UK
  Tel: 020 7381 9711
  Email: admin@bowelcanceruk.org.uk
  Web: www.bowelcanceruk.org.uk
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Stoma Care Open Days...

Open days give ostomates the opportunity to meet and share experiences with other ostomates. Many people attend with friends and family as they are very sociable events.

Date: 19th April 2012

Venue: Dunfermline Football Ground, Halbeath Road, Dunfermline, Fife, KY12 7RB

Time: 11.00am - 2.00pm

Organiser: Salts Healthcare
Trevor Donald
Email: tdonald2000@yahoo.co.uk

Date: 21st April 2012

Venue: Level 3, Academic Centre, John Radcliffe Hospital, Oxford

Time: 10am - 2.00pm

Organiser: Stoma Care Dept, Oxford Radcliffe Hospitals

Date: 17th May 2012

Venue: Swindon Town Football Club, Legends Lounge, Swindon

Time: 10.30am - 3.00pm

Organiser: Stoma Care Department Great Western Hospital

Open day events are posted on the Colostomy Association website throughout the year...
visit: **www.colostomyassociation.org.uk**

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Website:- www.sashstomabelts.com

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E-mail address: info@sashstomabelts.com Website: www.sashstomabelts.com

An operation for bowel cancer and a stoma inspired Caroline Bowder to write a play about it...

THE BODY...a play for today's BRAVE NEW WORLD...

After Caroline Bowder had a bowel cancer operation and a stoma five years ago she decided to write a play about it. Now her epic play, THE BODY, a funny, compassionate, yet bold interpretation of what goes on inside and outside the body before and after surgery, is to go on stage in Henley-on-Thames's Town Hall in July for a seven day run as part of the town's annual Fringe Festival.

In an interview she gave after learning in February that her play had been accepted for the festival, Caroline said, "I have to have something world-changing to make me write." In her plays, film scripts and novels she had already tackled big subjects like childbirth, Caesareans and the death of parents. Now it was cancer's turn. Her operation in 2007 had triggered that world-changing experience that made her see her own body in a different light.

"I saw the body as a community of organs, where, if one suffers all of them suffer in different ways or if one is changed the others have to change their way of doing things to try and help the bit that has been changed."

"The operation in 2007 changed the workings of the bowel for ever and it was then that I began to realise this thing about the community of the body. A year after that I had to have another operation for secondary cancer, which was on the liver, and there again I realised that it taught me more about the personality of the liver. It has this amazing capacity to rebuild itself if it is wounded and even if half or three quarters of it is taken away it can grow, regenerate."

In her play, Liver rallies the other organs to the fight and even challenges She, the "owner" to make a heroic, and successful stand against the invading cancer. "In my play the organs are doing their normal course of duty and they realise that they have been invaded by cancer, this horrible enemy that has arrived in the middle of them and wants to take them over, exercise power over them and destroy them. They fight but they are also changed by surgery. Parts of them are taken away and sacrificed and other parts have to relearn ways of coping. "Portraying them as characters is a way of dealing with that mystery, when you realise the body has had to change and it does change. You realise that it has an intelligence of its own."

Caroline, whose yearly scans show that she is clear of cancer, has been elected a governor for the Royal Berkshire NHS Hospital Trust where she had her bowel surgery. She has also spent the last two years looking for a theatre to put on her play.

"It's on a fairly Shakespearean scale. I must have sent it to 10 theatres. Some responded saying it was a brave idea, challenging, but I think they felt they could not cope with the subject. I wanted my consultants to endorse the play, to say that I had got the facts right and they did. They were tickled to see themselves in a play. The surgeon is a kind of God in the play as well as being the surgeon. I also gave a copy of the play to the stoma nurse who is quite a friend. Stoma nurses are wonderful because they are very supportive. They have seen it all, they are not shocked, they are just kind."

Caroline continued to search for support for her play, even travelling to Denver, Colorado where two directors liked it but did not commit themselves. Finally, she decided to form her own theatre company and she and her husband Bill, a partner in the company, have engaged a London theatre director, Andrew Harries for the Fringe production and have started fund raising. The first £100 came in last week.

"Art is expensive. Theatres are constantly running at a loss but I think to get the message across you just have to invest in it," Caroline said. "People might be shocked by the fact that I am dealing with it head on. I am showing how part of the large intestine has to be changed so that it becomes a stoma that has to wear a hat. One of the messages of the play is that the body is always beautiful."
" If anyone objects I will say to them, 'you do not know how many people have colostomies and you do not know how many people there are to whom poo is quite a preoccupation in a completely practical and day-to-day way and so, be educated!'"

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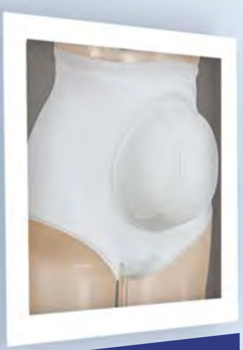

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It was whilst I was there that I realised 'support groups' were fulfilling a need – they are a vehicle for ostomates to come together – to chat, share, support and learn from one another!

Alfred Levy writes about.... his patient journey, how he was inspired to become a CA volunteer and how through his own endeavours he started the Ostomistics Support Group based in Stevenage

Like many other people who visit their doctors less regularly than they should, my family and I were shocked when I was diagnosed with bowel cancer. After a routine operation failed to cure or eradicate the cancer, I was told that my only real option was to have a 'colostomy'. Everything was explained to me relatively quickly and in what seemed like no time at all, I was recovering in hospital. I had a newly formed stoma and attached to it was a strange appliance.

There had been a few minor hiccups along the way. It seems I was given more than my fair share of anaesthetic so I was not quite my old self for a few days after my operation. When I came around properly I became fully aware of my new physical situation.

Pictured front row on the left: Alfred Levy - CA Volunteer and founder of the Ostomistics Support Group, Stevenage with members from the group

A complication had occurred – new surgical theatre stirrups had affected my leg muscles so I needed a few operations to remove the muscles in my shin, the cause, muscular compartment syndrome. I now have some permanent restriction in the movement of my feet. I had to wear splints for a while and for some weeks was hardly able to walk.

Five years on I cope far better with walking, but must remember not to try and run or I will inevitably fall over! The good news is that my surgeon believes my cancer has been removed and is unlikely to return. I had to stay in hospital for three weeks because of my leg condition, it was a really painful time.

Whilst in hospital I gained much from patient visitor and CA volunteer Robin Mills (a former trustee of the Colostomy Association). I had never before met anyone with a stoma. Robin offered reassurance that all would be well and gave me the confidence to get my life back on track. I knew my operation was irreversible so I was determined to enjoy life again.

I am not sure who gave me a copy of 'Tidings' whilst I was in hospital, it was either Robin or my stoma care nurse. I read it from cover to cover and have since, continued to do so. I was fascinated with other peoples stories. I read with sadness how some people seem to 'give up', unable to adjust to their new situation, whilst others have a much more positive outlook.

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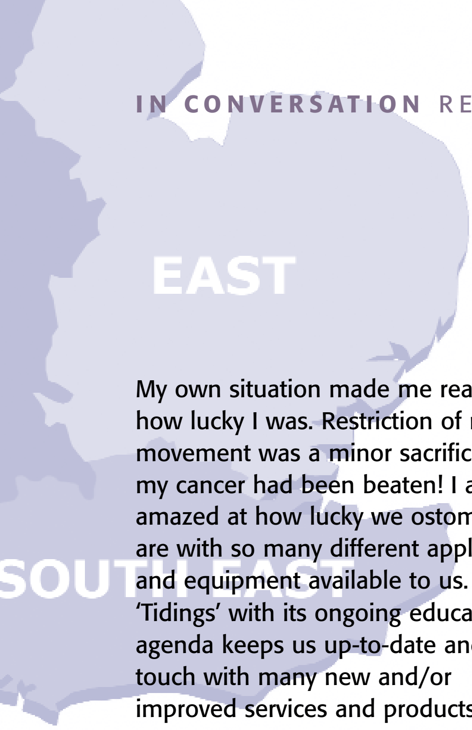

My own situation made me realise how lucky I was. Restriction of my foot movement was a minor sacrifice as my cancer had been beaten! I am still amazed at how lucky we ostomates are with so many different appliances and equipment available to us. In fact 'Tidings' with its ongoing educational agenda keeps us up-to-date and in touch with many new and/or improved services and products.

Within six weeks of leaving hospital I was able to drive again, returning to work and travelling to the USA on business, encouraging overseas companies to set up in the UK. I am now fortunate enough to be semi-retired and enjoy holidays all over the world. My confidence, fully restored, stems from my initial meeting with Robin and my introduction to Tidings.

Reading the back pages of Tidings I discovered that there were 'support groups' for ostomates spread around the UK. I looked up the nearest one to me - it was in Peterborough, called Ostomistics, only about an hour away from where I live. The main contact there is Heather Connor, whom I phoned and she invited me to attend one of her meetings. So I went to meet the group and I was really impressed, everyone was friendly and the atmosphere, well, it was incredible. I ordered six pairs of special boxer shorts from a supplier attending the meeting that I didn't even know were available or on NHS prescription!

It was whilst I was there that I realised 'support groups' were fulfilling a need – they are a vehicle for ostomates to come together – to chat, share, support and learn from one another! Heather explained how she started up her group and suggested that I try and start my own local group. She gave me a lot encouragement!

Later it hit home, how lucky am I, the 'cured' one! I have a future ahead of me…living with a colostomy...is not so bad after all!

I felt inspired! I wanted to be a patient visitor volunteer like Robin Mills. I wanted to form a support group like Heather's. I wanted to be a volunteer and help the Colostomy Association as they had helped me. I wanted to give back to society and really help others like me! But, how to go about it!

I attended several patient open days and spoke to a number of ostomy product manufacturers and suppliers. I looked up specialist websites and even tried to get the support of my local stoma care nurse. However, being an impetuous person, matters were progressing far too slowly. One stoma care nurse said I had no volunteer qualifications and could possibly harm patients. Others warned me of the problems relating to 'the Data Protection Act'. No one could give me names and addresses from their own databases, be they suppliers, manufacturers, or national support organisations, which is of course quite correct.

So how could I attract 'ostomates' in my locality? The Colostomy Association knew of my desires, as I had spoken to them on several occasions at patient open days, by email and phone. They invited me to attend one of their volunteer weekend away events, aimed at bringing together established and prospective volunteers – an earlier event had taken place at Chester (sponsored by ConvaTec) and had been a great success. This time the venue was in Huntingdon (sponsored by Dansac), it was an enjoyable event and I learnt much from attending, but it was training that I needed (this was to come later in December 2011).
So I went back to Heather for some ideas. She told me she had received help from a stoma care nurse! A 'flyer' written by Heather along with letters signed by the stoma care nurse were mailed out to prospective members by a well-known manufacturer of appliances in her local postcode area of Peterborough.

So I decided to contact my stoma care nurse and she kindly agreed to do the same thing. I drafted the letters and emailed them to her for approval. Then - the long wait! To my dismay the staff at the hospital had changed and my nurse had moved to another hospital 20 miles away. I contacted the stoma department again and got nowhere. That close feeling of co-operation had gone. Everyone was too busy and to my frustration it appeared I was not well enough qualified!

Then came the BIG breakthrough! The new and extraordinarily busy stoma care nurse suggested that I contact 'Ostomy Lifestyle' and speak to Helen Bracey. This changed everything. Ostomy Lifestyle had just received a grant from the National Lottery to train prospective 'support group' leaders on how to form a group.

Helen invited me to attend a training day in Milton Keynes with some other prospective group leaders. I learnt much more about the Data Protection Act and how to circulate information to those in my postcode. I discovered that I just needed to have organisations on my side that were prepared to do that for me. Helen also gave a presentation about the differences between a colostomy, an ileostomy and a urostomy. Finally she suggested how a successful group might function.

I went away from that day feeling much more positive. Then I heard from another member of their staff to say that they were about to send out their Newsletter and if I would like to write a flyer they would insert it in their Newsletter and send it to members living in my postcode area. It took me no time to produce the flyer and they helped me with the editing. The mail out resulted in a number of prospective new members.

I then asked my new friends at the Colostomy Association if they would mailshot the same flyer to their members in my postcode area and they agreed, as did a manufacturer. Within three weeks I had about 40 prospective members who phoned, emailed or wrote to me. Most were very keen, and guess what! – one of the prospective members living in my area was Robin Mills and even better he wanted to join, I couldn't believe it, I was delighted! Another prospective member was Judy Colston, an established CA volunteer who I had met at the Huntingdon event! My luck was changing!

I replied to every prospective member by post or email encouraging them to attend the first meeting in October. I booked a community hall but had no idea how many would attend, guessing I would be lucky if 15 or 20 people came. Imagine my shock when 50 people turned up - the emergency exits had to be opened up to accommodate everyone!

Heather came along and spoke to the members wishing everyone good luck! My group wanted to use 'Ostomistics' as their name and with Heather's groups' permission we were given the thumbs up! At that initial meeting I formed a management team to help me with the group. We carried out a survey as to members' wishes and whilst many were predictable I was surprised at the social nature of the rest of them. Some wanted meals out, sightseeing tours, theatre visits or to listen to talks on identified topics such as diet or from members who had interesting hobbies or lifestyles. None wanted meetings in a hospital environment. Even my stoma care nurse attended (the original one, who is still overworked and currently standing in for my new stoma care nurse due to illness) and is now a fully-fledged supporter!

To date we have 75 members and have an average attendance of 30. At each meeting we often see new faces. We now meet on the last Saturday of each month in a much bigger venue than we started with, a community centre in Stevenage. So far we have had four meetings and have a full programme for the next six months.

We are totally independent of manufacturers and suppliers, although we are considering asking a different company to attend each time with their products and are considering charging a fee for the privilege! We don't charge for refreshments or a subscription and the earlier management team has now become the committee.

We don't want to stop anyone attending because of cost. Partners and carers are always welcome to attend and are treated as members in their own right. We have a raffle at every meeting and donation boxes are scattered about the hall for members to donate whatever they feel is appropriate without any pressure from anyone. We organise lifts for those unable to attend where transport is not available and we are most grateful to Stevenage Council who gave us a grant in order to meet some of our initial costs.

The enthusiasm of the committee keeps the wheels of the support group oiled and now hopefully I can take a backseat role! I am delighted to say that I am no longer a prospective volunteer - I am a fully trained CA volunteer having successfully completed two CA volunteer training courses, in December last year. An Induction course for Volunteers and a Telephone Helpline course!

All that remains for me is to train to become a patient visitor, which would mean so much to me. I am certain I could make a difference to others prior to their colostomy surgery or afterwards and if necessary help others to regain their confidence, as I did with the help and reassurance given to me by Robin Mills during my early days of living with a colostomy!

The aim of this article is to encourage others to set up a support group in their local area. If anyone wants to contact me for further details please contact the Colostomy Association who can put us in touch. It really is quite straightforward to set up a support group once you identify the route!

All you really need is a little guidance, plenty of patience, determination and passion…the end result is extremely rewarding! Kind thanks go to everyone who helped me along the way to starting Ostomistics, Stevenage!

Alfred Levy

From the Editor

Overleaf is the list of support groups mentioned in Alfred's article. The list is regularly updated and the CA is always interested to learn about new groups and offers help to individuals interested in setting up a support group.

Support Groups are places where people can share personal stories, express emotions, and be heard in an atmosphere of acceptance, understanding, and encouragement. Participants share information and resources. By helping others, people in a support group strengthen and empower themselves.

Stoma support groups
in your region...

Information about Support groups is regularly revised. If you know of a **support group** not mentioned in our listings please get in touch...
e-mail: editor@colostomyassociation.org.uk

Scotland

Midlothian:
Maggie's Edinburgh
Contact: 0131 537 3131

West Lothian:
GOSH
Contact: Alex Topping 01501 772154

Glasgow:
Glasgow Stoma Support Group
Contact: Maureen O Donnel 01236 436479 or Charlie Sutherland 01698 822075

Ayrshire:
North Ayrshire Stoma Support
Contact: Jim 01292 220945
Stoma Care and Recovery (S.C.A.R)
Contact: Rhona 01294 557478 or Maggie 01294 271060 or Mob 0781 7736147

Fife:
Fife Ostomy Support Group
Contact: Ishbel Barr 01592 772200

England - North

Cheshire:
Cestrian Support Group
Contact: David Burgham 01244 310461
Stockport Support Group
Contact: Angela Simpson 0161 419 5059
TOMAS (The Ostomates of Macclesfield and Surrounding Areas)
Contact: Kath Wood 01625 875442
Warrington Ostomy Support Group
Contact: Jane Shaw 01925 662103

Cleveland:
Oops Group
Contact: Julie Morrisroe SCN/Carol Younger 01287 284113

County Durham:
South West Durham Ostomy Group Bishop Auckland
Contact: Betty 01388 814535
Jen 01325 311266 or
Maureen 01388 818267

Derbyshire:
Stockport Support Group
Contact: Angela Simpson
0161 419 5059

Lancashire:
Oldham Stoma Support
Contact: June Wilde 0161 312 5538
Trafford Bowel Care
Contact: Jackie Carey (Secretary) 0161 7489 659 Doreen 0161 9627 818
John 0161 7484 655

Merseyside:
Crosby Support Group
Contact: Stoma Care Nurse
0151 529 2842
Aintree Stoma Support
Contact: Stoma Care Nurse
0151 529 2842
I.C.U.P.S
Contact: Stoma Care Nurse
0151 604 7399

Northumberland:
Northumberland Cancer Support
Contact: Mary Miller 01661 842029

Tyneside:
NHS Molineaux Centre
Contact: Stoma Care Nurse
0191 2380011
Royal Victoria Infirmary Support Group
Contact: Gordon Weatherburn
0191 234 1109

Yorkshire:
Airedale Stoma Support
Contact: Jenny Shaw 01535 652516
or Sue Hall 01535 210483
Behind You (Calderdale& Huddersfield Bowel Cancer Support Group)
Contact: Stoma Care Nurse
01484 355062
CROPS (Colo-rectal ostomy & internal pouch support)
Contact: Gloria 0114 2879503
Dewsbury & District Ostomy
Contact: Janet/Eileen 0844 8118110
Rotherham Ostomates Caring Support
Contact: Karen 0788 0575758
Scarborough Stoma Support
Contact: Sister Jean Campbell 01723 342388 Amanda Rowe 01723 342446
The Hull and East Riding Colostomy Support Group
Contact: Pete Smith 07989 565335
and Pete Rennard 01482 793966

Isle of Man:
Stoma Support Group
Contact: Carole Cringle 01624 650212

England - Central

Buckinghamshire:
Milton Keynes Stoma Association
Contact: Bruce Pollard 01908 582563

Leicestershire:
Moving on (Leicester Royal Infirmary Colorectal Support group)
Contact: Wilf Patterson (Secretary)
01455 220344

Nottinghamshire:
Nottingham Colostomy, Ileostomy & Urostomy Support Group
Contact: Rosemary Brierley
0115 982 7868
Nottingham Stoma Support
Contact: Mrs B Heath 0115 966 3996
North Notts Stoma Support Group (Sutton-in-Ashfield)
Contact: Tore and Nicky Norman
01773 715460

Shropshire:
Oswestry Stoma Support group
Contact: Carole O'Ryan 01691 671624

Staffordshire:
Outlook
Contact: Ernie Hulme 01782 324441
Joan 01782 710828

Worcestershire:
Kidderminster & District Collossus Support Group
Contact: Brendon Drew 01299 400843

West Midlands:
Coventry Stoma Support
Contact: Martin Robbins
02476402616
Newhall Stoma Support Group
Contact: Sarah French 07773 396236
02476402616

England - East

Bedfordshire:
Saturday Social Club
Contact: Karen Richards
01234 792278

Cambridgeshire:
Ostomistics
Contact: Heather Connor 01733 768332 Mob: 07757167422

Essex:
Connect
Contact: Lin Hart 01279 505273
M.E.S.S (Mid Essex Stoma Support)
Contact: Paul Foulger 01245 224374
Jeanette Johnson 01376 511862
N.E.S.S (North Essex Stoma Support)
Contact: Mr K Harvey (Chairman)
01206 271425
Brian Waller (Secretary)
01206 540449
Optimistic Ostomates
Contact: Janet 01702 385510 or
Angela 01702 385509
South Essex Young Ostomy Group
Contact: Paul Gray 01708 501268
STEPS
Contact: Jackie Coleman
01268 451937
Redbridge Ostomists Club
Contact: Stoma Nurses: Chris/Lisa 020 8970 8321

Hertfordshire:
Connect
Contact: Lin Hart 01279505273
Colonise
Contact: Gill 01727 851556
Hertford Stoma Support Group
Contact: Ralda 01992 535311
Stevenage Ostomistics
Contact: Alfred Levy 01767 316958

Lincolnshire:
Friends Support Group
Contact: Betty 01205 724120/Sheila 01205 364493
Grantham Stoma Support Group
Bobbie 01476 464822

Norfolk:
Ostomy Friendship & Support Group
Contact:
01553 770288/768271/775698
Ostomy Friendship Group of King's Lynn
Contact: 01533 691370/768271 or 01533 775698
Stars
Contact: Anne Browne 01603 661751

Suffolk:
East Suffolk Ostomy Group
Contact: Marion Fisher 01473 311204
James Pagett Ostomy Support Group
Contact: Sandra Hutchings 01502 585955
West Suffolk Support Group
Contact: Jessica Pitt 01638 515525

England - South East

Berkshire:
Monday Pop In Group (Bracknell)
Contact: Jackie Dudley 01344 426652
WBOC (West Berkshire Ostomy Club) (Reading)
Contact: Jackie Dudley 01344 426652

Hampshire:
Solent Ostomates Support Group
Contact: Carole Summer 07527 707069
Wessex Urology Support Group
Contact: David Morris 02392 361048

Isle of Wight:
Optimistics
Contact: Stoma Nurse Lynne Webb SCN 01983 534009
Semi Colon Bowel Cancer Support Group
Contact: Tony Crowson Chairman
01983 244656

Kent:
Ashford Stoma Support
Contact: Ron Huckstep 07941 310681
Margaret Webb 01233 628807
Atoms Support Group
Contact: Maria Culleton SCN
01227 769679 or 07827997424
Canterbury & Coastal Stoma Support
Contact: Marie Culleton SCN
01227 769679 or 07827997424
Dover & District Stoma Support
Contact: Marie Culleton SCN
01227 769679
Dover Stoma Friends Group Support
Contact: Julie Bell & Ros Marshall
07771345701/01233616646
Maidstone Stoma Support Group
Contact: Judy or Kirsty
01622 224305

London:
Bowel Cancer Newham
Contact: Scyana 0208 5535366
Homerton Hospital Bowel & Stoma Support Group
Contact: Toni Johnson 0208 510 7599
Angela Davy 0208 510 5318
Shepherd Bush Stoma Support Group
Contact: Roslyn 07984979728
or Mary 07773397234
Whipps Cross University Hospital
Contact: Christina 0208 5356563

Middlesex:
Inside Out
Contact: Bob (Chairman) 0208 4284242 Sarah Varma 0208 2354110
Semi-Colon Club
Contact: 01895 179391

Oxfordshire:
Oxfordshire Ostomy Fellowship
Contact: Pat Longworth 01235 524163

Surrey:
Epsom & District Stoma Support Group
Contact: Jan/Sheena 01372 735232

Sussex:
(SAS) Brighton & District Stoma Care support
Contact: Sylvia Bottomley 01273 554407
The Ostomy Friends Group
Contact: Jane Quigley 01323 417400
Ext 4552

West Sussex Princess Royal Stoma Support
Contact: Tina Walker 01444 441881
Ext 8318

England - South West

Avon:
B.O.S.S Bristol Ostomy Self Support
Contact: Christina 01179 075326
Joyce 01179 558236 Rob 01179 668021

Cornwall:
Ostomist and Carers Support Group
Contact: Christine Davey
01208 831471
Optimists
Contact: Sue Hatton 01326 340058

Devon:
Devon IA
Contact: Margaret Bond 01392 447374
Devon Stoma Support Group
Contact: Donna Ashbrook
01626 854862

Dorset:
CUPID (Colostomy Urostomy pouch Ileostomy of Dorset) Christchurch
Contact: CA for details 0800 328 4257
Cupid (Colostomy Urostomy pouch Ileostomy of Dorset) Poole
Contact: CA for details 0800 328 4257

Wiltshire:
Swindon IA
www.swindon-ia.org.uk
Wessex Stoma Support Group
Contact: Michael Slater 01722 741233

Wales
Blaenau Gwent Self Help
Contact: Celia McKelvie 01873 852672
Bridgend Ostomy Patients Support Group
Contact: Jackie Walker 01656 660 801
Royal Glamorgan Stoma Care Support Group
Contact: Domenica Lear
01443 443053
Swansea Ostomy Self Help Group
Contact: Glynis Jenkins 01792 418245

Northern Ireland
Causeway Patient Support Group
Contact: Mary Kane 028 70346264
Daisy Hill Hospital Newry
Contact: Bernie Trainor
028 3883500 Ext 2222
Mater Hospital Belfast
Contact: Karen Boyd
028 90741211 Ext 2329
Southern Trust
Contact: Mary Jo/Bernie
028 38612721

Eire
Bowel Cancer Support Group (Irish Cancer Society)
Contact: Olwyn Ryan
+353 12310500
Mayo Stoma Support (Castle Bar Hospital)
Contact: Marion Martyn
094 902 1733

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