

WINTER 2013 | Issue 28

Tidings

colostomy association

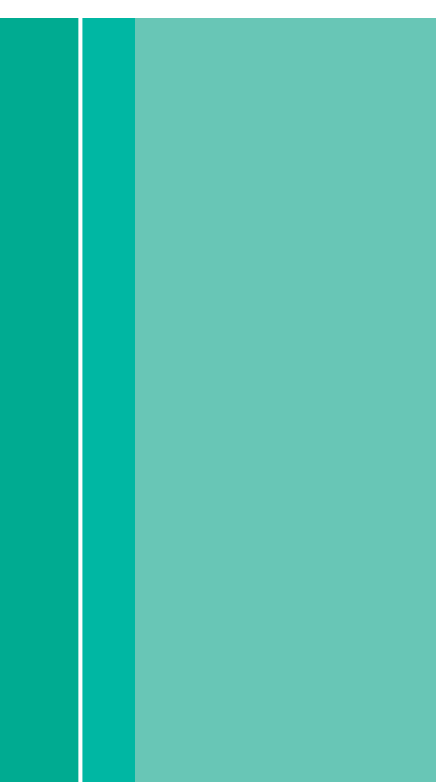
Dedicated to Colostomates their Families and their Carers



Cover story...
Take two women

Feature
How to feel
good about yourself

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welcome to WINTER

An interesting story...



The CA received an early christmas greetings card with the above picture enclosed. As I am an inquisitive soul I wanted to learn more. I discovered that Sally-Anne has been a supporter of the CA since 1999 but that's not all, as you can see from her picture, Sally-Anne is all dressed up and here is the reason why....

Sally Anne Odell is a direct relative of the Odell family who disembarked at Cobh when the Titanic anchored on April 11th 1912. Five of the Odell family who met Fr. Francis Browne onboard, came ashore with him to enjoy a motoring holiday in Cork.

And there's more...Last year as MS Balmoral arrived at Cobh on the coast of Ireland - on its way to the wreck site of the Titanic – Sally-Anne was on board, hence her lovely costume! Her family took what is thought to be the last photograph of the ill-fated ship, which never reached its destination, New York.



Happy New Year! Welcome to the winter issue of Tidings...

As another year begins it's difficult to focus on what's ahead as the past year has been so exceptional!

The Queen's Jubilee birthday celebrations and the inspirational London 2012 games have celebrated all that is good and beautiful, uniting and gladdening the hearts and minds of people across the UK and around the world. The common denominator 'people' – who gave themselves up to making these two events memorable the same can be said for Tidings magazine. For without YOUR letters, emails, stories, fundraising efforts, educational articles, product information...Tidings simply wouldn't be the publication it is today!

During 2012 I again had the privilege to attend several healthcare/stoma care related conferences as Editor of Tidings – but this time there was someone missing. That someone was Sue Hatton Executive Trustee of the Colostomy Association. You see over the years that I have been involved with the Association I have worked with Sue on various projects and events. Her enthusiasm and empathy for bringing quality information to colostomates knows no bounds. Sue had several major operations in 2012 and is now on the road to recovery I am sure like me you all wish her well!

YOUR amazing contributions to Tidings have brought tears to my eyes on many occasions. It is important to note that through YOUR 'real lives' stories, Dear nurse queries and

Readers' writes you have changed peoples lives for the better - YOU have made a difference to others through the pages of this magazine.

I would like to thank my Editorial team for their ongoing support, they keep me focussed on the detail, their passion, ideas, observations and articles shine out from the pages of Tidings.

I would also like to send out several BIG messages of thanks and appreciation...to our Dear Nurse...Julie Rust – thank you! Julie always makes time to answer your medical queries even though she is exceptionally busy.

A big THANK YOU to the advertisers who without their continued support, Tidings magazine in its current form would not be possible! And last but definitely not least, kind thanks go to the unsung heroes who continue to ensure the highest quality of production and print that this publication truly deserves!

Tidings magazine extends a warm hand to YOU and to everyone involved in stoma care and to the ostomy community in its widest sense. Tidings is proud to provide a discussion platform that reflects and considers aspects surrounding the ostomate and stoma care.

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



Email:
editor@colostomyassociation.org.uk

PS. For details of how to get in touch with the Editor of Tidings and the Colostomy Association – please turn to Page 6.

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all your regulars



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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:



Join our 'closed' group today...

simply put Colostomy Association into your FACEBOOK search bar, click on Group and click on 'Ask to join' you will be assured of a warm welcome!

Visit us 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.



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 939 1537

Publication:

Spring	April	2013
Summer	July	2013
Autumn	October	2013
Winter	January	2014

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Tidings Magazine:

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

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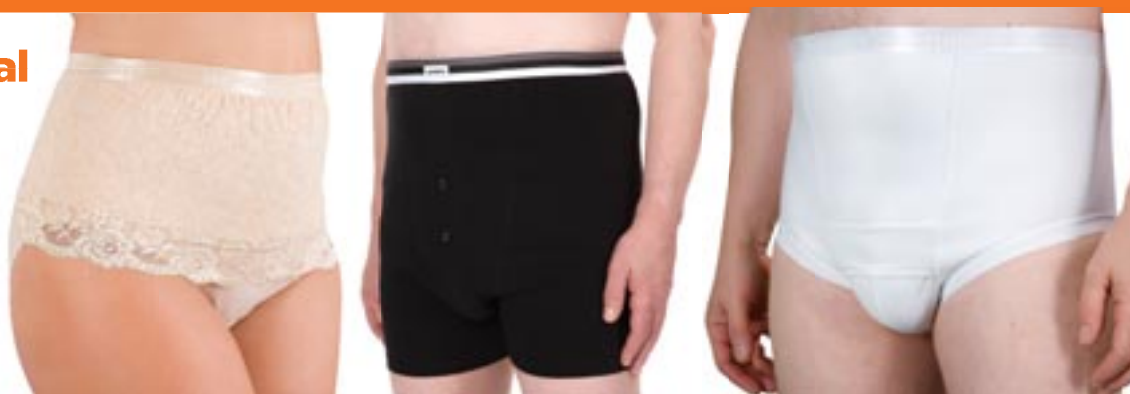


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COLLECTION



Message from our President...

I am very encouraged by the hard work done by our Association during 2012. I applaud the continuous striving to reach out and support ostomates across the UK and further afield. Although the Colostomy Association is a lesser known charity its heart is big – many colostomists lives have been changed overnight by the support given by our organisation. Indeed I am increasingly convinced that better lives for colostomists depends upon organisations such as our own, and upon the willingness of our members to come forward and support the various initiatives that the Association puts forward.

I continue to visit and operate in many countries throughout the world. Visits this year have included Germany, Barbados, France, Czech Republic, Switzerland, USA, Italy, Qatar, Malta, Serbia, Poland, Belgium, and Austria. The list never seems to stop. In last years address I mentioned something that is very close to my heart. I am sure by now

you all know my enthusiasm for colostomy irrigation and my unerring desire that every colostomist is made aware of the potential advantages this bowel management method has to offer patients.

I am delighted to tell you that filming for the two Colostomy Irrigation DVDs took place in August last year at Pelican Cancer Foundation and Basingstoke and North Hampshire Hospital. A short excerpt from the proposed Colostomy Irrigation DVDs (Colostomy Irrigation: a reference tool for clinical nurse specialists (stoma care) and Colostomy Irrigation and You: an educational DVD for healthcare professionals and patients) was launched at WCET UK (World Council of Enterostomal Therapists) UK Conference (now the Association of Stoma Care Nurses UK – ASCN) in Edinburgh and was seen by more than four hundred stoma care nurses. The content was very well received and the CA team attending the event took advance orders.

The Association of Coloproctology of Great Britain and Ireland this year covered topics ranging from sore bottoms, pelvic floor disorders, radical and not so radical treatment of rectal cancer, colonoscopy, Crohn's disease, emergency colorectal surgery and the thorny issue of what to do with a polyp containing a focus of cancer. There was much stimulating debate amongst the speakers at the end of each session, prompted by cases presented for discussion.

Our Vice President, Mr Ian Daniels FRCS of the Peninsular Medical School in Exeter (an established

international expert in the repair of all forms of incisional and stomal hernias) orchestrated a Masterclass in June at the School with the focus being on the issues surrounding prevention and repair of parastomal hernias. The event was very well attended by eminent surgeons and research fellows who outlined a variety of surgical techniques. Interactive discussions on choice of mesh and complex abdominal wall reconstruction were included as was the stoma therapist and patients perspective of parastomal hernia. The latter having a great impact on those attending.

Finally, I think we all need to express our Christmas good wishes and thanks to the people who work in the Colostomy Association office and who commit themselves to the running of the Association in many different ways. Tidings is a marvellous magazine, and I look forward to seeing what you have to contribute to it during 2013.

Seasons greetings and a very Happy New Year to everyone!

**Professor Bill Heald OBE
President
Colostomy Association**



Message from our Chairman...

In late 2011 we said 'Goodbye' to Richard Bray who sadly retired due to ill health and to Gill Herbert who decided to move on to pastures new.

2012 has been quite a year again for the Colostomy Association! Sue Hale started with us in January as our new General Manager (Sue brings her expertise of working with various charities/volunteers to the CA). Long standing staff member Jo McKenzie has been recognised for her hard work and promoted to Senior Administrator (volunteer co-ordinator). In April, Jane Wood our Tidings Editor and Design/Publicity 'guru' joined the Association to work in-house in a full time position – having previously worked for the Association for some seven years in a client based relationship with husband Mike in their Design/Marketing business. We are also delighted to welcome our newest recruit – Jo Hammond who joined the CA office team in July to provide additional administration support to what is always a busy and vibrant office.

I am delighted to report that CA has increased its volunteer strength and now has over 100 volunteers. This has been due to several induction and

helpline training programmes, the last being completed in November in Birmingham.

Trustees are very excited about the future of the Colostomy Association. As a result of this activity and the fact that the lease of our offices at London Court expires in March we are in the final phase of negotiations to move to recently refurbished premises with increased floor space, located close by. These larger premises will enable CA to provide much needed in-house facilities such as a meeting room, volunteer training facility and dedicated telephone helpline area. They will also provide a better working environment for permanent staff, visiting and office volunteers, and guests. Plus increased storage and despatch capacity for patient literature and Tidings magazine. Being able to bring everything together under one roof will allow CA to streamline its activities and as a result make further use of valuable funds.

Our mission for 2013 is to continue to reach out to more ostomates and provide them with the support and reassurance they need both pre and post operatively. The number of stoma procedures carried out is increasing annually due to improved diagnostic technologies. We will, with your help, continue our work to ensure that all those patients – need never feel they are alone – but are aware of the Colostomy Association and the difference the charity can make to their wellbeing – via its trustees, staff and in particular its volunteers and the support they provide.

With all Good Wishes to you all for Christmas and the New Year.

Monty Taylor
Chairman
Colostomy Association

A few soundbytes from Trustees...

Jackie Dudley – Trustee and Volunteer....

I am passionate about providing support pre and post-operatively to colostomates – you just cannot put a price on it. My own experience of knowing that I was not alone 'living with a colostomy' helped me immensely with my recovery. I now run two support groups in Berkshire to ensure that there is always somewhere ostomates can meet and make friends with others who feel as they do.

Mary Thomas
Trustee, Volunteer and Helpline...

In June this year the Trustees held their annual strategic planning meeting to agree the CA's focus for 2012/2013. My role, ahead of each meeting is to draft a list of proposed activities intended to help us deliver our objectives. We'd love to do everything on our list but our limited finances and staff/volunteer resources force us to focus on what are our absolute must do's – followed by our should do's and finally by what would be nice to do. It sounds simple but heat is generated when we have so many competing priorities – please rest assured that no blood is shed in the process!

Duncan Wells
Trustee, Volunteer and Helpline...

The Facebook group which started the year with 248 members now numbers 748 and is a tremendous source of support for ostomates – a real family. The success stories of people being helped through the experience and advice of others are legion. More importantly members discover that they are not alone. Sarah Squire and I are the admins. Well we're more like proud parents really. I have given a few talks this year, one of which was to a Rotary Club in Nottingham to explain 'living with a colostomy' and to see if they might add us as one of the charities they will support. I believe they will so that was a success. The helpline calls have been mainly about product supply issue and so I take up cudgels on their behalf.



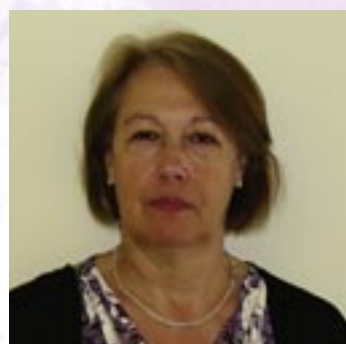
Sue Hale
General Manager



Jo McKenzie
CA Senior Administrator
(volunteer co-ordinator)



Jo Hammond
CA Administrator



Jane Wood
Tidings Editor
PR& Comms Manager

Dear Readers...As this is the New Year issue of Tidings Magazine – we thought it would be a good time to introduce YOU to the CA office staff...

General Manager – Sue Hale, Jo McKenzie and Jo Hammond look after the day-to-day running of the office, manage the volunteers and action the many and varied requests. Jane Wood – Tidings Editor and PR&Comms Manager constantly reviews incoming queries, articles and letters, which come into the CA and to Tidings magazine, researches NHS changes and other health related information and manages all media enquiries. There is never enough time in the day – so say all!

The following is a flavour of what takes place in the office on a daily basis:

CA Postbag...letters, donation forms, requests for information, thank you cards – are all delivered by our postman – who is awaited with keen anticipation.

General telephone enquiries and helpline enquiries....Staff answer a variety of incoming calls ranging from simple requests for travel certificates and photo ID cards to more in-depth calls on topics such as fistulas and rectal discharge. CA is very experienced at taking these in-depth calls and although the CA cannot give medical advice, staff interpret the callers needs so that they are listened to carefully, given information or sign posted on to the relevant person or resource e.g. stoma care nurse, GP, consultant or other supportive organisation/charity. In some cases, depending on the nature of the call (and with the callers permission) the office may suggest to a caller that they might like to speak to a fully trained CA volunteer with 'real life' experience of the callers problem. The volunteer will be able to offer practical advice and give reassurance and support. The CA's aim is to ensure no one need ever feel alone or unsupported. International enquirers are often referred on to worldwide stoma support organisations.

Email...the CASS email box is always busy. Daily requests cover a wide range of topics. CA volunteers may email in with open day information or patient literature requests. Articles or requests for Tidings also come in via this route and much more besides!

CA Website...this provides another pathway into the CA office. Online requests are received for patient literature from health care professionals and new supporters. Online donations also come in via this route and require processing. The website itself is constantly updated with relevant and new information, patient open day events and support group information changes.

Liaison with stoma care nurses...many requests come into the office from stoma care nurses all over the UK. CA patient literature is in high demand as are CA volunteers who may be asked to visit a patient pre or post op or attend a patient open day event. This ongoing relationship with stoma care nurses is extremely important to CA.

CA volunteers...staff co-ordinate the 120 strong team of dedicated fully trained volunteers spread out across the UK, some of whom have been trained to man our 24 hour helpline, others may be asked to make ad-hoc phone calls to those who enquire about specific stoma care topics or problems. Volunteers also represent the CA at numerous events, attend patient open days and fundraise for the CA! Organising a team of 120 CA volunteers to attend the numerous UK wide manufacturer, hospital patient open days and Journal of Community Nursing (JCN) Workshops is sometimes challenging but very worthwhile – the feedback from those attending is so rewarding! Each event attracts a wide range of attendees and gives our volunteers the opportunity to reach out to colostomates and nurses alike who may never have heard of the Colostomy Association.

In November 2012 ConvaTec kindly sponsored a volunteer induction training event, which took place in Birmingham. Twelve new recruits attended and they all passed with flying colours and are now fully-fledged CA volunteers, which is wonderful! Recruitment is now on hold to allow us to focus on our existing volunteers.



Local volunteers...Several local volunteers help out regularly in the office. They are invaluable and greatly assist with the workload – currently we have Claire, Colin, Terry and Margaret (who has an ileostomy and is pictured above) says: 'I have been an admin volunteer at CA

– H/Q for about two and a half years. I help out most Fridays wherever I am needed. Although some of the work is repetitive e.g. stuffing envelopes, the best part of the job is when I have been able to help someone over the phone. Just getting a person to realise they are not alone is so rewarding and I really do understand some of their problems. Listening to these folk is often humbling and has made me realise how lucky I am. It also keeps the old brain cells active – working as I do with younger computer savvy folk. Believe me - this small office and team is a dynamic force of action, compassion and information, which I find inspirational!! In short I gain far more than I try to give'.

Support and advice for setting up new support groups...The team is delighted to advise and help anyone set up a new ostomy support group across the UK. The office has some very useful information and volunteers willing to talk about how they set up their group are available.

Fundraising support...the office is always interested in any fundraising activities associated with the CA, as we are an independent charity financed solely by donations. We would encourage those of you who are taking part in various activities such as marathons, skydives, quizzes or BBQs to get in touch we have sponsorship forms available!

Manufacturers' mailshots...

these regularly flow in and out of the office – advertising open days or new products. The mailings vary in quantity, sometimes just 50 come in, other times 5,000. They generate much needed income for the CA. Our local volunteers can regularly be seen sitting behind a desk in the office sticking address labels on to large piles of stamped/sealed envelopes!

In early 2013 the CA will be moving office having been at London Court for five years. Our refurbished offices will be larger, providing a better working environment for staff and volunteers, giving more space for storage and allowing us to hold training sessions and in-house meetings which will allow CA to make further use of valuable funds.

Every call, email, letter or online request receives an answer the same day – information is despatched overnight...all requests are carefully dealt with to ensure no one is left without an answer or information!

If you would like to support the work of the Colostomy Association please donate today online at: www.colostomyassociation.org.uk, via telephone: 0118 939 1537 or fill in and return the donation form on page 47 – many thanks.

Photo ID Card...

This new photo ID card is proving very popular as it can be useful if challenged when entering or exiting accessible toilet facilities.

If you would like to apply for a Photo ID card, please complete the form opposite and return it to the CA for processing with the various enclosures.

Alternatively, the form is downloadable from our website. Please allow 10-14 days for delivery.

National Key Scheme (NKS) Radar Key and optional Photo ID card...

To obtain a **key or an ID card** please **complete the form and declaration**. Make your **cheque payable** to the **Colostomy Association**. Return all required items to: **2 London Court, East Street, Reading, Berkshire RG14QL**

(Any queries please contact the CA office on: 0118 939 1537)

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DECLARATION: I declare that the individual named above is chronically sick, has a disabling condition or has had a bowel or bladder diversion that necessitates the use of disabled toilet facilities. The key is for the personal use of the above named and their designated carer only.

Signature of self or carer: _____

Date: / /2013

The misuse of any public or private conveniences constitutes an offence. Please note that there are penalties for making false declarations. Key holders' details are stored in accordance with the Data Protection Act and may be randomly checked by the Association



Please **tick** the following as appropriate:

- ☐ I would like to receive a key for a charge of £3.50 (including postage and packing).
- ☐ I would also like to receive an optional photo ID card for an additional charge of £6.50 and enclose a passport ID photograph.
- ☐ I attach a copy of my prescription or recent delivery note as proof of eligibility and a cheque made payable to 'Colostomy Association' in the sum of £3.50* key only/£6.50* ID card only/£10.00* both the key and ID card (*Please delete)

Please cut along the dotted line and return to the address on this form - thank you

Pathways to a Colostomy...

Take two women – mother and daughter. The daughter...Maria Adaway...born with a dual rectum, underwent many surgical procedures to try to remedy the problems it caused. In her thirties Maria decided to have a permanent end colostomy. The mum...Julie Carter...rushed into hospital in 2011 in agony with a perforated colon following a bout of acute diverticulitis received an end colostomy...life changing?

Stella Scordellis SMS Creative Photography



L-R: Julie Carter (Mum) with Maria Adaway (Daughter)

A trip booked a year in advance now looked as if it would have to be cancelled – this is their story... Into Africa

Readers'
PANEL
contributor

July 2011. It was all arranged. Booked, a year in advance. In July 2012 I was going on safari to Uganda and Rwanda with my mum Julie, her brother David and her friend Barbara. We were going to see the chimpanzees of Kibale and the mountain gorillas made famous by Dian Fossey and the film *Gorillas in the Mist*, then on to Kenya, to see the orphaned elephants in Nairobi.

The itinerary was mouth-watering, but rather daunting. Boat trips and game drives, night walks and hill climbs held out the promise of seeing much of Africa's exciting wildlife as well as the big apes, but the hours that would be spent bouncing along rough roads in jeeps and trekking through hilly jungle terrain would require stamina. Still, it wouldn't be all 7 hour drives and 9 hour treks. The words cosy lodge, swimming, sunbathing, and relaxing by the river also made their appearance. So that was all right, then.

We couldn't wait. And we'd be back in time for the Olympics. What could be better?

And then, in November 2011, Mum was rushed into hospital in agony with a perforated colon following a bout of acute diverticulitis, and ended up having to have an end colostomy. She was in hospital for 2 weeks, and then for another couple of days when she was hit by severe pain and it was thought at first that something had gone amiss.

It was debatable whether, at 70, she could recover from such a battering in time to cope with the physical

demands that our projected trip would entail but, ever a fighter, she was thinking about her recovery from Day one. She had always been fit, and she was sure that the activities she enjoyed, such as Aerobics, Line-dancing and Pilates, would stand her in good stead. However, she was dismayed to find, as the days progressed, it was still impossible to walk to the end of her road without having to sit on a wall for a rest.

'I can't do this.' The thought was beginning to creep into her mind more and more often.

The weather was bad; certainly not conducive to taking the walks she knew she'd have to do to get herself fit enough to do the trip. If she couldn't walk to the end of her road, how was she was to stand any chance of tracking gorillas in the wilds of Africa without collapsing in a heap? And how would she cope with a colostomy bag on safari, when facilities for changing might be few and far between and she was still only just getting used to dealing with it?

'At that point,' Mum says, 'I didn't think it would be possible. I was sure I'd have to cancel.'

Not if I had anything to do with it. A runner for many years, I was knowledgeable about the necessity of training. I knew all about starting slowly and building up, and I was determined that Mum wouldn't have to miss out on something she'd been so looking forward to.

Accordingly, on a snowy day at the end of February, we began our



Maria Adaway...pictured with the magnificent mountain gorillas of Rwanda

training programme. Living on the North Downs in Surrey, you can't go anywhere without encountering a hill. It's a steep pull-up from my house to Kenley Airfield, but once you're there, it's nice and flat. We began by going once round, then twice, then further afield.

'Not so fast.' Mum was still finding it tough going, but I didn't let her slack.

'Come on, woman, keep up!'

Now, I know what you're thinking. How unsympathetic can you get! It's all right for her. She's younger, she's a runner so she's fit, and she isn't an ostomate. How can she know what Julie's going through?

Wrong! I know exactly what it's like because I also have a colostomy bag. Have had for the past 9 years.

Unlike the reason for Mum's colostomy, mine was congenital. I was born with a dual rectum and underwent many surgical procedures to try to remedy the problems this caused. It seemed to get more active in my thirties, after the birth of my two boys, James and George, and

when I took up running. After a sphincter repair (without a temporary colostomy or ileostomy) that went horribly wrong in 2000, I had another sphincter repair with a temporary ileostomy. However, the sphincter was past help by then. I had the ileostomy for three years after which, in 2003, I decided that it would be easier to have a permanent end colostomy.

Even with this history, it took a year or more to fully come to terms with having a bag, and it was nearer to two years before I felt confident enough to go swimming. The triggering moment came while I was enjoying a pampering spa weekend, when the changing facilities were so close to the pool area that I decided to give it a go. Since then, I've competed in 4 triathlons, dozens of races both on road and cross-country, and a fair sprinkling of the sort of events in which mud, obstacles, mud, thigh-deep water and mud tend to figure prominently. The only thing I baulked at was the formidable Marathon des Sables, and that was less because of the difficulties of managing a bag in those conditions and more to do with the bit on the entry form which asked what you wanted done with your

body if you died during the event!

'If it hadn't been for Maria's advice and support, I don't think I would have contemplated going to Africa,' Mum admits. 'I was still at the stage where I needed to lay everything out in front of me before I could change my bag, whereas she could discreetly let air out without anyone being aware of what she was doing, or even change the bag in the corner of a crowded room if push came to shove. She taught me to always carry spares and the indispensable wet-wipes, and told me to use a radar key that I already had for my son, who has disabilities, which would let me into locked disabled toilets. Sometimes, having a basin in the cubicle to wash in can mean all the difference between comfort and soreness.'

When organising the trip, we were told we weren't allowed to take plastic bags into Rwanda. Obviously, used colostomy bags would be very unpleasant if they weren't put into plastic bags first, so we took paper Sanitary Towel bags into which we could just dump the whole lot, plastic bag included, knowing they would be incinerated without anyone looking to

Pathways to a Colostomy...



Julie Carter...pictured with one of the guides

see what was in them. I also found out about the Colostomy Travel Certificate, from the Colostomy Association, which enables you to take the bags through Customs, with reasonable confidence that they won't wave them around and ask in loud tones what they're for! It was only by chance that I was told about this Certificate, despite having been abroad quite a few times since I'd had the colostomy. Maybe some more publicity about it from the CA wouldn't come amiss?

Anyway, Africa it was.

We landed at Entebbe International Airport and drove for 7 hours to the Primate Lodge, a five-minute walk from the Kibale Forest National Park Headquarters. The first couple of days went smoothly, apart from having to dodge a moth as big as my hand, which was flapping around the bathroom, and discovering, when I went to get into bed, that it was already occupied. It took quite a while and a fair bit of shooing to round up the lizard and evict it to the right side of the mosquito netting.

At breakfast on the second day, with cars expected any moment to take us on a long game drive to the Kasenyi Track in the Queen Elizabeth National Park, Mum felt the trickling sensation

around the stoma which told her something was wrong. Her bag was filling up rapidly and overflowing. She went to the bathroom to change it. And change it again. And again.

I came to the rescue with Imodium Instant capsules at the ready. I'd had the sense to eat poached egg on white bread toast for breakfast; Mum had succumbed to the lavishly heaped bowls of luscious exotic fruits. Over-indulgence in these can produce ructions in any alimentary canal. When you have a bag on the end, the results can be deeply unpleasant. But, the Imodium having stemmed the flood, Mum felt more comfortable and was able to enjoy the rest of the trip.

And she learnt to adapt her eating; more eggs, less fruit, washed down with Imodium in the morning. Four pints of cider and a curry are a no-no under most conditions, but it's all so very individual that what one person can ingest with no effect will cause havoc with another's digestive system. There were a couple of further times when, if she had been in England, she would have had to dive behind a bush, but it's not so easy in the African veldt, when you never know what might crawl, spring or slither from the shrubbery. But she gained in confidence and dealt with it.

And was it all worth it? You bet it was! The animals of West Africa seemed determined to reward us for not giving up when everything seemed hopeless. We have so many memories to treasure, like the regal silver-back gorilla just metres away, looking on benignly while one of his younger offspring tugged at David's shorts. Crocs, looking deceptively dormant on the riverbank. Hippos, wagging their ears and showing off their impressive tusk-like teeth. Elephants, antelopes and a moseying lion; warthogs and hyenas, fruit bats and chattering chimps. And Mum's favourites, the little Ellies wearing their chequered coats at the Elephant Orphanage in Nairobi. Move over, David Attenborough.

'There can't be that many mothers and daughters who both have colostomy bags,' Julie says. 'Maria's very up-front about having a bag. Knowing that she has never let it stop her doing anything she wants to, and that she would be there to give me practical day-to-day advice made the world of difference when I was deciding whether or not to go on an ambitious trip like that so soon after having the operation. But I'm so glad I did! If I could cope with everything from altitude to leaking bags, I can cope with anything. Now, I just get on with enjoying my life.'

And I've discovered that there are times, when loos are few and far between, that having a bag can be a distinct advantage!

Editors Comment

**Don't forget
your FREE
Travel
Certificate**



general enquiries :0118 939 1537
or e-mail your request to:
cass@colostomyassociation.org.uk

Brava™

“I didn’t think
I could find
a tape that
would fit my
body shape.”

Steve, an ostomate since 2003

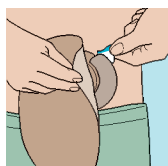


Think again. Think Brava™

Now there is an elastic tape that prevents baseplate edges from lifting

The new Brava Elastic Tape is elastic, which enables it to follow your natural body movements while keeping the baseplate in place for extra security. The new elastic tape is skin friendly and can also prevent the baseplate edges lifting, which can mean longer wear time.

Brava Elastic Tape is part of the new range of accessories from Coloplast, designed to reduce leakage and take care of your skin.



How to use

Apply the Brava Elastic Tape to the baseplate and the skin where desired. Remove the remaining protective paper and smooth the tape onto the skin to ensure the baseplate is kept in position.

See full instructions for guidance on how to use this product.



Sign up for free samples at brava.coloplast.co.uk
or call our customer care team on 0800 220 622

www.coloplast.co.uk

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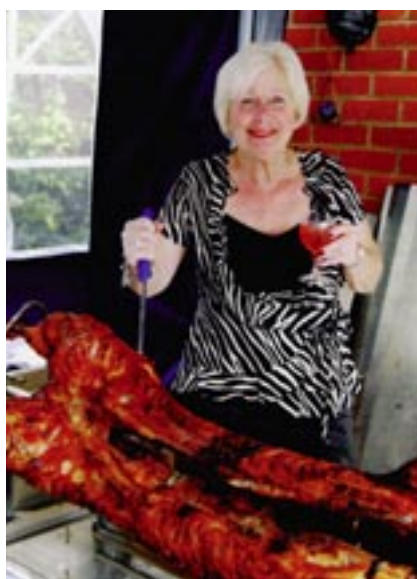
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Donations
When sending your
donation/s please mark
your letter/cheque with
Tidings Issue 28....
Thank you!

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...

Sandra's Second Hog Roast...



Last year, I celebrated my birthday, and fourth anniversary of my colostomy by hosting a hog roast, with proceeds donated to the Colostomy Association. I was pleased to put something back into the organisation which has helped me since my operation, and, in fact, shortly afterwards, became a volunteer – attending Open Days and manning the CA Telephone Helpline.

Possibly, against my better judgement, I decided to repeat the event and with the expert help of my soon-to-be son in law, a butcher, it was arranged for 2nd September when we welcomed over 100 people into our garden, hoping for fine weather.

My husband and friends had erected a number of gazebos, and with tables

and glasses borrowed from the local scout group, we were ready for a sociable afternoon which resulted in a profit in excess of £1300 for the Association. As well as the hog, potatoes and salad, there were several desserts to choose from and inclusive drinks at a cost of £16 and, although it was hard work, the help from others in clearing and washing up made it all worthwhile and we have already set the date next year, for what seems to have become an annual expectation amongst our friends!

We also received support from Homestyle and Hollister, amongst others in providing raffle prizes and we, and our guests, are delighted with the result and this further assistance to the Association.



Linslade Bowls Club...President Day Event

The President of the Linslade Bowls Club in Leighton Buzzard recently held their annual Presidents Day event. The event was attended by members and guests who participated with the objective of raising money for charity. The President had no hesitation in nominating the Colostomy Association as the chosen charity as he had first hand knowledge of the Association as his wife had undergone an emergency Hartmann's Procedure due to Diverticulitis. The efforts from everyone involved raised the generous sum of £220.00, which will go to help the CA to continue its good work – supporting fellow colostomates 'living with a colostomy'.



Fundraising update in memory of Bob Buckley...Colostomy Association Volunteer!

BOB BUCKLEY RESEARCH FUND

The Fund was set up in January last year in memory of Bob Buckley, long standing volunteer of the Colostomy Association. The funds raised so far are courtesy of his family and friends.

The Fund welcomes continuous donations as the monies raised will be used for specific research projects and will be a living legacy for Bob's family, while benefitting others longer term.

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 visit:
www.justgiving.com/kevin-buckley78

Monies raised to date for the Fund amount to £4239.00... thank you everyone!

Research can make a difference!



CA Volunteer – Derek Oakey

recently celebrated his 70th Birthday and raised £130.00 in lieu of presents!
Nice One Derek!



Johnson Wax Ltd Charitable Trust...

We are happy to support the work of the Colostomy Association please accept our donation for £1000. We wish you continued success with your fundraising activities.

**Regards from
The Charitable Trust Committee**

Dear Tidings, Coffee Morning....

I am pleased to be able to send you a donation of £500.00 which has been raised from this event.

J.M

Dear CA, In Lieu of Christmas Cards...

I am pleased to be able to send you a donation of £10.00 which has been raised from this activity.

Mrs J.A

Dear Sir, Sir Jeremiah Coleman Gift Trust....

We are pleased to support the CA with a donation of £75.00.

Dear Tidings,

I am pleased to be able to send you a donation of £50.00 in support of the CA and Tidings.

K.P

Dear CA,

Please accept a donation of £370.00 in support of the CA.

Mrs G.W

Dear CA,

Please accept a donation of £300.00 in support of the CA.

Mrs A.R

**Thank you
everyone
for your kind
donations**

500 Club... September 2012 Draw Winners!

Anonymous	£ 268.00
Mrs S Tanner	£ 134.00
Mrs J Neal	£ 53.60
Anonymous	£ 53.60
Mr G Williams	£ 53.60
Mrs J Pearson	£ 26.80
Mr C Allum	£ 26.80
Mr R Tucker	£ 26.80
Mrs J Ball	£ 13.40
Anonymous	£ 13.40
Mrs R Penketh	£ 13.40

Legacies...

Mrs K Rivens £ 5,000.00

Thank you

Coventry Leofric Lion Club...

A donation of £1140.00 was raised for the Colostomy Association by newly appointed CA volunteer – Martin Robbins and Team who completed the Coventry Telegraph Walkathon. The event which has been taking place for some 16 years has raised £185,822.68 for local charities and good causes.



About the Leofric Lions...Lions Club

International is a community service organisation dedicated to the idea that the men and women who live in a community are in the best position to know who needs help and why. Local Clubs are part of the world's largest such organization, with 1.4 million members serving in more than 180 countries and areas.

The Colostomy Association would like to say...

A big **THANK YOU** to everyone who donated and raised funds on our behalf during 2012. We try to publish as many letters as possible - to those of you not mentioned here...you are not forgotten - we wouldn't be here without your help - **So, PLEASE keep up the GOOD WORK in 2013!**

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

Inspired...by the Olympics! Bruce takes up archery in his 70th year!

As long as I can remember I had wanted to try my hand at archery. So when I finally retired at the grand age of 69 I felt that it was a good time to get started.

To my delight I found there were several clubs in the Milton Keynes area and Silver Arrow Archery in Edlesborough seemed to be the most progressive. It offered regular beginners courses, an indoor and outdoor range, a well stocked shop and a travelling distance from home of just 14 miles. I chose to bypass the taster session and enlisted for the compulsory beginners course. This course consisted of 4 x 2 hour sessions using mainly a recurve bow (such as they were using in the Olympics at Lords) but also an introduction to the longbow and compound bow. On completion of those four most enjoyable introductory lessons I felt very much engaged with the sport. I realised that I finally had an interest that I could devote time to and hopefully reach a level of competency that would enable me to shoot in club events.

Perhaps at this stage I should mention a little about myself and about my stoma. With schooldays in Bedford behind me I left to follow my dream of a nautical career. From the age of seventeen my studies took place in the School of Navigation at Warsash on the Solent. From there I joined the NZ shipping company to train as a Deck Officer. Hard work was involved but of course it gave me the opportunity to travel the world. In time the lure of loved ones enticed me back to home waters and I joined Esso Petroleum Co. to work on their coastal tankers. But after a few voyages left life on the ocean wave to settle into married life with my wife Maureen and subsequently two children. A couple of years in Barclays Bank followed but that life was not for me and I joined our family business, a



traditional Ironmongers based in Bletchley. Most of my working life was spent either there or in another company, which specialised in woodworking machinery and computerised industrial wood copy lathes, which we imported from Germany.

All in all an active, interesting, happy life until early one morning at the age of 53 I was suddenly struck down with intolerable pains. The distressing sequence of events which followed me into Milton Keynes General Hospital and continued for two days on a general ward, were mainly suffered by my wife as I was too ill to amass any recollections. A rapid deterioration eventually prompted further action and the emergency operation resulted in major surgery for a perforated intestine.

Three weeks in an induced coma plus a further three weeks in intensive care went by, until I was well enough to be transferred back to a general ward where I stayed for a further six weeks. It had been a close shave with my wife being told in the early days that I only had a 20% chance of survival - but thanks to the marvellous surgeon, Mr. Ed Walker, I lived to tell the tale. My recuperation period was slow, with most main organs having to reimpose

their functional roles. All had been a great shock to the system and circumstances did not allow for any rational preparation relating to stoma surgery before my operation. Learning to live with a stoma is a process - certainly the help and support from family is vital. Considering the gravity of my illness I believe myself to have been extremely fortunate in living a pretty normal life since that traumatic event.

I have been able to continue with my family (now with the addition of six lively grandchildren!) and business life with very few problems. Yes I still become disturbed about the odd leak, the occasional unpleasant odour, the strange noises, the growing hernia and the worry of another blockage - but hey! I'm alive and always seek to confront any concerns in a positive manner. At times I read of the distressing conditions some of my fellow ostomates have had to endure and I really count my blessings.

I felt a great need to repay the hospital for the wonderful care I had received whilst in their hands and so spent several years helping out as a part time volunteer in their League of Friends shop. Some years later I spent five years as chairman of Milton Keynes Stoma Association. I still wish

to continue my charitable work and so in November this year I was accepted by the CA as a fully fledged volunteer, after attending their volunteer induction training course in Birmingham.

Now, back to my archery - a year on and using my longbow I now manage to consistently hit the 50 yard target! Arrow making is also taught as a one day course at the Club's premises and I now get much pleasure in making my own wooden arrows. You can often find me in my shed at the bottom of the garden with a handful of feathers, cedar shafts, metal points, nocks and the appropriate tools. A few hours later I emerge with another full set of arrows for the quiver. The next course I hope to attend will be the two day course for making wooden bows.

Monthly competitions are another aspect of Silver Arrow that I very much enjoy and it's great that archers of all ages can compete and enjoy the sport in a competitive, strict but friendly atmosphere. If anyone would like more information on archery please feel free to contact me via the CA office (details can be found on page 6). If you would like to learn more about archery you can visit: www.silverarrowarchery.co.uk

I look forward to being an active CA volunteer and giving my support as a positive oostomate to others who have suddenly found themselves in a similar situation to my own.

Bruce...treats us to an overview of his new pastime...

Types of archery...

Target archery: Target archery: Targets are set at pre-arranged distances with a certain number of arrows being shot at each distance depending on the round to be shot. Everyone shoots on a given command and similarly collects their arrows all together. Scoring is on 5 colour zone target faces; gold, red, blue, black and white concentric circles, with either 5 or 10 scoring bands that are determined by the type of round. An inner 10 is now provided for the compound bow archers.

Clout: This requires the archer to drop their arrows into a scoring area 24 feet across on the ground at a distance of 180 yards for men, 160 yards for

women and 120 yards for juniors. There is a peg holding the clout flag. A cord is attached to the peg, so it can be rotated around the scoring zones. You score one, two, three, four and five as you move in towards the middle and in the middle is a tiny white target which gets you six points if you can hit it. Where the arrow shaft enters the ground is the position taken for the scoring value. A clout round is 6 ends of arrows, (6 x 6 arrow ends = 36 arrows total.)

Field archery: This normally takes place in undulating or wooded terrain. Archers move around the targets in groups of around four. The archer stands with their lead foot against a post in the ground. There may be one post for the target or four at the same distance in a "fan" or posts at different distances. You may be told the distance - marked round - or it may be an unmarked round, where you have to judge the distance for yourself. Every shot may be from a different standing position with natural obstructions to overcome in order to hit the target. You may shoot at target faces, different sizes of animal and bird pictures or 3D rubber animals of different sizes.

Targets can be set-up on the sides of hills, making the judgement of the actual distance to the target difficult, especially for the unmarked round.

Bow Types...

Recurve: The Bow that most archers begin their archery career with. This normally involves a riser, which can be made of wood, aluminium or carbon fibre plus limbs made of wood, foam or carbon. A recurve archer will normally start with aluminium arrows and progress up to carbon/aluminium mix ones later. A range of accessories can be added to the bow including sight, stabilisers, bowslings, pressure button and clickers.

Compound: The most modern of bow types. Very popular in the USA, South Africa and Eastern Europe where animal hunting is still allowed. (It is illegal to shoot at any animal or bird with a bow in the UK). The compound has a cam system, which allows the archer to pull a heavy weight, which reduces to just a few pounds at full draw. There are accessories specific to the compound, which include release aids, peep sights and magnified sights.

Longbow: The traditional style of bow, which is growing in popularity again. The bow is a single "D" shape and is

normally around 72" long. It can be made of a single piece of wood, or two to five laminations of different woods. The longbow archer will shoot wood arrows. There are few accessories to add to the bow, but many longbow archers like to use traditional style accessories for themselves such as leather armguards and leather or linen quivers.

Arrows...

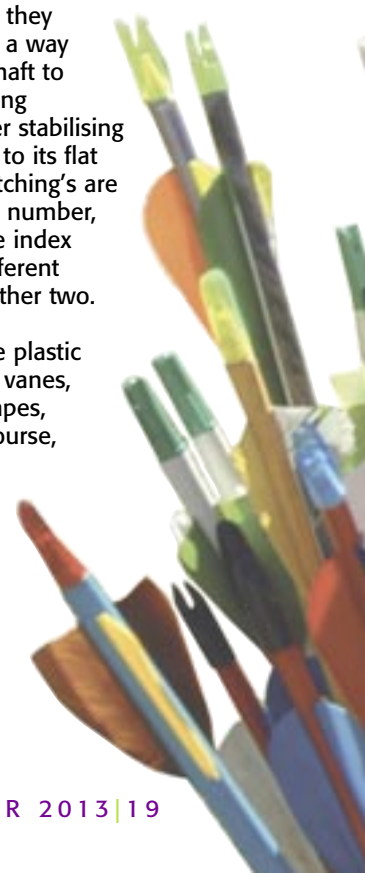
Arrows in the recurve (Olympic) bow events can travel in excess of 150 miles per hour, while compound arrows can fly in excess of 225 miles per hour. The shafts are made of either aluminium or aluminium with carbon fibres. Aluminium arrows are more uniform in weight and shape, while carbon arrows fly faster and provide less cross-wind resistance, and are therefore more useful in long distance outdoor archery.

One end of the arrow is weighted and tipped with a target point, designed to penetrate but a short distance in the target butt. The other end features a nocking point, a plastic cap glued or otherwise attached to the end of the arrow. Its fingers grip the string until flung loose, and it provides a protection for the shaft by deflecting hits from later incoming arrows. This generally destroys the nock, but leaves the arrow reusable. Sometimes, of course, the aim is too perfect to deflect; the resulting "Robin-Hood" is both spectacular and expensive, as both arrows are usually destroyed.

On the shaft itself fletchings are glued to stabilise the arrow's flight. Sometimes they are glued in such a way as to cause the shaft to spin around its long dimension, further stabilising its flight at a cost to its flat trajectory. The fletching's are generally three in number, one of which (the index feather) has a different colour than the other two.

Fletchings may be plastic 'feathers' or solid vanes, in a variety of shapes, lengths and, of course, colours.

Bruce Pollard



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.

New Soft Convex Medium Size Pouches - Now Available From Peak Medical Ltd

Peak Medical Ltd, exclusive UK distributor of the EuroTec range of ostomy products and accessories is pleased to announce the arrival of their medium size soft convex pouches. Closed and drainable pouch options now available on NHS prescription.



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 57 or call Freephone 0800 652 0424 and quote code M53 to receive your complimentary sample*.

Alternatively, please visit Peak Medical's website: www.peakmedical.co.uk for more information.

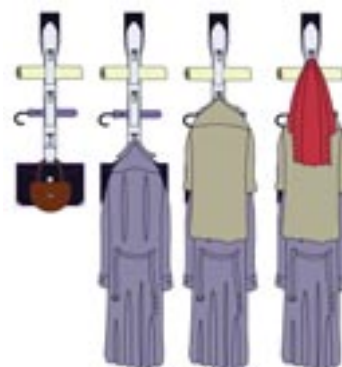
***All convex products should be used upon the advice and guidance of a Stoma Care Nurse.**

Invented and developed by an Ostomate...for Ostomates!

Tidy Pal is an award winning answer to the lack of hooks in toilets and changing rooms and weighs less than an apple.



Tidy Pal fits any type of door (for stall doors and partitions there is a special hook included) and needs no tools or fixing. Easy to use and fully portable it will support heavy winter clothes, an umbrella, newspaper and bag (Shopping, Lap Top, handbag) plus an Ostomy supply bag. After use, it folds into its own case.



For more information, please visit the web site <http://www.tidy-pal.com> or e-mail sales@tidy-pal.com or phone 0795 431 8944

A NEW product from Coloplast that deodorises and lubricates your appliance...

'As an Ostomate, you want to make sure the odour is neutralised and that output is led effectively away from your stoma to the bottom of the bag. A build up of the output around the stoma can lead to pancaking, which in turn may lead to sore skin and leakage'.

For this reason, we have launched a new edition to the Brava™ accessories range. The Brava™ Lubricating Deodorant neutralises odour and is multi-lubricating. The multi-lubricating effect ensures content moves to the bottom of the bag and away from your stoma. It also makes it easier to empty your bag.

We have a complete new accessory range...

The new lubricating deodorant is part of the new and improved Brava range of ostomy accessories from Coloplast. All products have been designed to reduce leakage or take care of your skin.



To order a free sample of the new Brava Lubricating Deodorant or to find out more visit www.brava.coloplast.co.uk or call us on 0800 220 622.



NEW products from OstoMART now available on Drug Tariff!

Following the success of the 50ml size OstoMIST Mint Drops Odour Neutraliser, OstoMART has now launched a new 25ml travel size version. OstoMIST Mint Drops contain a powerful odour neutralising enzyme, called Nanozyme, which effectively breaks through faecal odour and also has a refreshing and powerful spearmint and peppermint fragrance. Prescription order code for a 25ml bottle is SPN6.



OstoMART has added the colour NUDE to their popular range of Cool COMFORT Unisex Light Control Support Garments, designed to give light support after surgery. They are available in a Boxer, Pantie Brief or Waistband option and also come in Black and White and in sizes S/M, L/XL and XXL/XXXL.

OstoMART – new additions to our range of pouch covers. CoverSURE LIGHT are made from 100% peached polyester microfiber with an antibacterial and antimicrobial finish and are available in White, Black or Beige. The CoverSURE PLUS has a leak resistant but breathable inner lining and is available in White or Beige. All our pouch covers are custom made to fit your stoma pouch.

For a FREE sample of OstoMIST Mint Drops or for further information about the Cool COMFORT or CoverSURE range, please call freephone 0800 220 300, email: enquiries@ostomart.co.uk or visit our website: www.ostomart.co.uk

Independence Products Ltd...re-vamp their website! Increased information about their stoma care accessories and more user friendly...



If you would like to learn more...about them, their accessory products, or if you have an enquiry or simply want to request some product samples then please go to www.independenceproducts.co.uk You can also contact Independence Products on 0115 975 7254 or send an email to enquiries@independenceproducts.co.uk.



**Hello everyone...
I'm Molly and I have a
colostomy...and have
suffered with Crohn's
disease and M.E from
a young age...I would like to
tell you about myself and
my stoma 'Neville'...**

Molly was formally diagnosed with Crohn's when she was 13 but had been suffering with M.E. for the previous two years. The combination of both conditions meant she was unable to attend school for the four years from year 7 to year 10. Molly found herself either battling with severe Crohn's symptoms or totally exhausted from M.E. In year 10 her condition improved sufficiently for her to return to school in time for her GCSE's. This is her story.....

I was either battling severe Crohn's symptoms or totally exhausted from M.E. I have had three major flare-ups of Crohn's disease – each one reduced my body to a devastating low. The biggest flare up was so severe it caused me to be admitted to hospital for eight weeks as my body had become seriously malnourished. I was then put on the 'Elemental Diet' - which is basically having no food and just drinking foul tasting nutritional drinks. My medication was changed several times – mostly resulting in only temporary improvement. In 2009 during my A-Levels, my Crohn's flared again and I was readmitted to hospital. My consultant then suggested we try Infliximab infusions – I am happy to say my Crohn's has not returned since!

That should have been my happy ending with Crohn's, but no such luck! Although my Crohn's was still inactive, my colon, rectum and anus were very damaged. During my GCSE's I noticed that I was leaking and constantly needing to go to the loo. After telling my consultant and trying various treatments none of which worked, I was referred to a Professor who specialised in this area. He conducted an Anal Dilation and I had to continue self-dilating at home but it failed to change my situation. Living with constant leakage and the urge to go to the loo nearly all the time was horrendous. I had no social life, I couldn't go anywhere, I had to be near a loo, as I had to go numerous

times a day. I also had to wear pads, which I changed frequently day and night as I suffered from nocturnal leakage. I am amazed I got through my 'A' Levels – it was tough. I have memories of arriving at college and waiting in the car until my urging stopped and then having to dash straight to the loo before class. It was hard in class – I tried to listen but at the same time suppress my urging by squeezing every muscle in my body without people noticing.

In my final year of college we went back to see the Professor to discuss what else could be done. Out of nowhere he said that realistically the next step was to form a stoma. He explained what it was with little empathy but I think I zoned out – I was so stunned by this suggestion that I was silent the whole way home.

A fantastic nurse who has looked after me for years suggested a second opinion from a local consultant. He was lovely and explained what he believed to be going on in my tummy in a clear, empathetic and knowledgeable way. He explained that having a stoma was possibly the best idea for me but thought we should try Sacral Nerve Stimulation first, sadly this was unsuccessful.

I always remember when the consultant walked out of the door after our meeting – he shook my hand and gave it a reassuring squeeze and said 'don't worry; we'll get to the

bottom of this.' One of the many fantastic things about him was that he always made time for my parents and I. I never felt our appointments were rushed. He listened to our concerns and made me feel I was in good hands. I will always be so grateful to him and his team at the hospital for their empathy and professionalism.

In August 2011 I said yes to having a permanent colostomy. Walking out of the hospital after making that decision, I felt terrified but determined that it was my time to live the life I deserved. I had a meeting with the wonderful stoma care nurse team (before my operation) to be marked with a cross to site my stoma and to see the bags I would have to use. Afterwards I burst into tears. I think that I had been living in a bit of a naive bubble about life with a stoma and hadn't realised how major the surgery was.

On October 12th 2011 I arrived at the hospital with my amazing Mum – my wonderful Dad couldn't come in with us. I put on my very fetching stockings and hospital gown and watched the time tick by. Then it was time to go! The Anaesthetic Room was filled with lots of people, I gave my Mum a smile and I drifted off to sleep.

The operation that was supposed to be four hours long actually took seven hours. My tummy was a challenge to work on and my consultant was very near to deciding to do open surgery but luckily it was all done using keyhole techniques. The first night I had a severe reaction to the epidural. I struggled to breathe and my recovery was delayed as the pain relief method had to be altered to oral medication. I was very weak afterwards and I was on so many painkillers I just wanted to sleep all the time. The stoma care nurses came round each day to help me change bags and when I felt a little stronger I tried to change the bag on my own – I burst out crying as I suddenly saw my stoma for the first time but the next day I changed it all on my own and felt very proud of myself!

Once home I slept a lot but I was improving and in a short space of time I was doing things I could never have dreamt of doing before my operation. I was walking and standing much more, going to the loo frequently was no longer a problem and I could sleep the whole night without having to worry about pads.

It was incredible! I have now become very attached to my stoma and have named him Neville! I decorate my bags, which causes much amusement to people when I show them!

I am now nearly 20 and have a transformed life. I have learnt to Irrigate, which has given me much more freedom. I have a job waitressing, which is something that would have been impossible before Neville!

The Colostomy Association has been really supportive throughout especially over the early months with Neville (my stoma!). It has been a steep learning curve managing Neville's habits and tantrums – when I had any questions or just wanted a chat with people in a similar situation – the Colostomy Association was there for me!

I knew after I had my stoma surgery I wanted to get fit and definitely climb Snowdon along with my family and my dog Maizy - who have supported me through some very tough times.



Molly with 'Neville' pictured on the slopes of Mount Snowdon

I completed my climb up Snowdon last May! I have little muscle strength, as I have been unable to participate in any form of activity since age 11 so Snowdon was a big challenge! I have to say it was the best experience –

really hard but the views were outstandingly beautiful.

When I reached the top it was such an achievement and I thought, 'if I can do this, I can do anything!' I don't regret having 'Neville' at all. I wanted my life back and I knew what I had to do in order to achieve just that – it was daunting but the pro's outweighed the con's by a million miles!

It was a great moment on top of Snowdon – but what was even greater was knowing I was raising money for such a deserving charity. I am still fundraising and to date have raised £800.00 if you would like to add to this amount please visit: www.justgiving.com/MollyandNeville

Update from Molly... Since writing this article I have started University and I am now officially a student child health nurse. It was a big adjustment moving away from home and having to fend for myself! It took time to settle in but I am a lot happier now and I am very much enjoying my course. The course is hard work and full of long days with a high workload that is only set to increase but I have a passion to be the best nurse I can be and to help children who are going through a tough time in their lives. This time a year ago I could not have imagined I would be at University and managing my stoma on my own! I have been irrigating since January 2012, since learning irrigation I can adjust it to suit my needs and the hours I have to work on my course – it is a lot more flexible than I first thought. 'Neville' has been well behaved most of the time – of course he has his moments when he is bad and causes me added stress but my life is 100% better with him – so I can live with his temperamental moments! Having 'Neville' in my life has on the whole been great and certainly makes my life more interesting – no day is the same living with him!

Irrigation and you...

Sue Hatton Executive Trustee writes...the most rewarding thing about being responsible for the irrigation page is the wonderful emails, letters and calls I receive from so many people...telling me how they are getting on with colostomy irrigation – or not! So please do keep your correspondence coming...along with any hints and tips you may have.

Sue writes...I have been a passionate irrigator since 1998, when our President Professor Bill Heald OBE, gave me a permanent colostomy. His ward sister, Ann Leppington Clarke, a whisper of a woman and an ileostomate, told me, six weeks after my op, that we were going to irrigate!

Sister Ann frogmarched me down to a tiny loo, with a drip stand in tow along with all the paraphernalia needed for my first lesson in colostomy irrigation! After that lesson I never looked back and over time became more convinced that this was how colostomates could enjoy a brilliant way of managing their bowel after stoma surgery.

As I became more involved with the CA, I would get on my soap box and sing the virtues of flushing out the bowel. I knew that for some irrigation was not a possibility and realised too that it may be a step too far for others, but even with that said I felt sure that everyone who could potentially irrigate should be made aware of colostomy irrigation and be offered the choice and opportunity to try it!

Having thought about it long and hard as to why colostomy irrigation is not offered more widely to patients. I decided that the problem might lay with stoma care nurses. I began to consider their time constraints and confidence levels – perhaps they were unsure about when to offer colostomy irrigation to their patients and how to teach colostomy irrigation.

A seed of an idea began to build in my mind – what if this were true – at various conferences and meetings I attended on behalf of CA I would ask these pertinent questions to many healthcare professionals. It became clear that there was some truth in my assumptions – so what could I do that would raise the profile of colostomy irrigation! Then it came to me – a DVD was needed to highlight the benefits of colostomy irrigation with a toolkit to support best practice of how to teach it to patients. Jane Wood and I worked very hard to obtain sponsorship for the DVD. Jane took on the job of liaising with the stoma

product companies to raise the necessary funding, but I'll let her tell the story of how it has become a reality!

Jane writes...In March 2011 a draft document was written by myself outlining the concept of two DVDs about Colostomy Irrigation. The concept was put forward initially to Coloplast to obtain funding. I am delighted to say that CA was given a generous educational grant to more than help get the project off the ground. Funding from Dansac was also sought to aid completion of the project. Kind thanks go to both companies for their insight and recognition of this important piece of information support for patients and stoma care professionals.

At the outset I decided that the content, storyboard and production could facilitate a dual-purpose outcome. The Colostomy Association worked with stoma care nurse advisors – Amanda Gunning RGN/CNS (stoma care) and Wendy Osborne MSc, RGN, ENB 216 (stoma care) and Lucy Russell RGN/CNS (stoma care) to ensure the content was clinically accurate and the rationale of Colostomy Irrigation was reflected.

I negotiated with Professor Bill Heald and Sarah Crane CEO of Pelican Cancer Foundation to secure filming facilities within their offices – this was given freely. I also negotiated with Basingstoke and North Hampshire Hospital and the lovely Emma Maltby RGN/CNS to film her and utilise their stoma care clinic. Filming took place last August over two days. Thanks go to all those who gave their time freely and appeared in both DVDs – Professor Bill Heald OBE/Pelican Cancer Foundation/President of the Colostomy Association. CA Volunteers and Colostomy Irrigators: Judy Colston, Douglas Haywood, Helen McTurk, Martin Robbins and Sarah Squire. Stoma Care Nurses: Juliette Fulham RGN, BSc (Hons), CNS, Heatherwood & Wexham Park Hospitals NHS, Amanda Gunning RGN/CNS Chelsea & Westminster Hospital NHS Foundation Trust/Volunteer SCN for the Colostomy

Association, Emma Maltby RGN/CNS Basingstoke and North Hampshire Hospital NHS Foundation Trust, Hyacinth Thompson RGN/CNS, Queen's Hospital, Romford. Special thanks go to Sarah Crane CEO – The Pelican Cancer Foundation, for providing the film venue, to Duncan Wells for the voice over recording and to Resolution Television for their patience and professionalism.

The outcome is as follows:-

DVD 1: An educational tool for healthcare professionals and patients – raising awareness of 'Colostomy Irrigation' as an alternative method of bowel management.

DVD 2: A reference tool for healthcare professionals already working in or training towards working in stoma care – raising awareness of 'Colostomy Irrigation' as an alternative method of bowel management.

A short excerpt from the DVDs was launched at WCET (World Council of Enterostomal Therapists) UK Conference in Edinburgh last October and was well received by over 400 stoma care nurses. Final editing took place mid December and the DVDs will be available in early 2013.

It has been quite a journey to get this project to fruition but one that I am very proud to be associated with!

Sue continues...Last July I had to have major surgery to get rid of pre-cancerous polyps in my colon and had to have an ileostomy, no more irrigating! Unfortunately, my bowel stopped working and after nearly four months in hospital, I am being fed by tube, nil by mouth and have a urostomy bag and a night bag to collect my liquid stool. So I missed all the filming, all the exciting bits! The gang have kept me up to speed with what's going on and I know it will be fantastic – my heartfelt thanks to Jane, Duncan, Mandy and everyone in the CA who took part, I can't wait to see it. Again, I urge any of you, who don't know about irrigation, to get our leaflet or ask your stoma nurse and see if you are able to give colostomy irrigation a try!

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CA FACEBOOK 'closed' group... making a difference to people's lives....

10.00am Sunday morning, at home and there is a notice that someone wants to join the CA Facebook Group. I click on her Facebook Page to check her out. I don't know why we do that because a Facebook Page only tells you what the person wants to tell you and if they were suspicious they would hardly say so. She is a young woman and gives quite a bit of detail about her school and so forth. She is admitted to the group and welcomed. Seconds later she posts. It's unusual for new members to post straight away but I can see why she does.

She has a 21 month old boy with a loop colostomy, they were recently discharged from hospital after a nine week stay but now they are back

because he has very sore skin. Nothing is sticking and so the soreness is getting worse. 'Does anyone have any idea what we can put on the skin to protect it and help it to heal? Could we post a picture to show everybody what we mean?' Pictures of stomas are not allowed on the CA Facebook Group.

I message the girl privately and tell her this and ask if she can edit the photo so as to show the soreness of the skin but not the stoma. She has just taken the photo on her phone in hospital and editing it is not going to be easy. No other Admins are available to discuss this with and so I make the decision that she should show the photo and we will remove it

once the group have seen it and made their suggestions. The photo is posted, the group get behind the problem and the comments pour in. There were something like 122 comments and about 20 remedies suggested. By the end of the afternoon the girl announced that they had managed to get a bag to stay on for 3 hours. The next morning they had stretched this to 8 hours and the skin was beginning to heal and the little boy was suffering less. That's what Facebook can do for people. And as I posted on the group, it makes me very proud to be a part of this.

CA FACEBOOK Group members meet again...

11.00 am Saturday 10th November, Cadbury's World, Bournville and thirty of our CA Facebook Group members are sitting in a tiny train as it winds its way around a world of tiddly, comic book, cocoa bean characters that are squeaking at us in a 'Pinky and Perky' kind of way over a sound track of sugar coated music.

It is the day of the great Facebook Meet. And we are having fun! Next will be a presentation at Salts Healthcare and a tour of the factory followed by supper at the Premier Inn. This is our second Meet. The first in April this year was such a success that we had to do it again. And this Meet was a success too! So it looks like two Meets a year are on the cards for the future.

For some the Meet was the first time they had ventured far from home, or the first time they had met up with other ostomates. There was no one present who could honestly say they didn't have butterflies in their stomach at the prospect. But for some it was much more than that.

It was something that they would never have done before and never believed that they might do. The power of the CA Facebook Group, the intensity of the friendships that are created and the support that every member gives and is given, overcame their fear of the unknown and they were there. Terrified possibly but there, nonetheless. And once again I felt terribly proud to be a part of such a group.

Sarah Squire (CA Facebook admin monkey and volunteer) and I had organised the events and Adrian Priest and Salts Healthcare had very kindly provided the funds to pay for the meal. Paul Seavers ran a fun,

'Name the chocolate Bar' competition and thanks to his generosity in donating a prize, raised £42. Then many of the diners - those that could - donated the refundable deposit that we ask for when they book a place and we were able to give the office £264.20. The Meet is not a fundraising exercise but it was a bonus to be able to give something to the Colostomy Association. Now Sarah and I must get on with planning the next one...

Duncan Wells
Trustee

Join the CA 'closed' FACEBOOK group today... simply put Colostomy Association into your FACEBOOK search bar, click on Group and click on 'Ask to join' you will be assured of a warm welcome!



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FAQs – Getting back to normal...

Do I need different clothes?

Most colostomates are able to find suitable clothing in ordinary retail outlets and High Street stores. However, there are companies who manufacture specialist clothing for colostomates.

These include:

- high-waisted trousers for those whose stoma is at waist level.
- underwear which is high-waisted or with an internal security pocket.
- support garments to prevent or control a parastomal hernia.

Will I be able to return to my job?

Once you have fully recovered, providing there are no other medical implications, there is no reason why you should not return to the job you did before you had your colostomy. Your doctor will advise you when you are fit enough.

If your work is strenuous and involves lifting heavy weights, or puts a strain on the abdominal muscles, there is a risk that you may develop a parastomal hernia. Consult your stoma care nurse who will probably suggest you wear a support garment and avoid heavy lifting whenever possible. However, if you have to lift something remember to place your feet apart (one foot in front of the other), keep your back straight, bend your knees and keep the object you are lifting close to your body.

After surgery it's normal to feel tired more quickly even if you are not doing strenuous work.

Will my driving be affected?

You should wait until at least six weeks after your surgery before you start driving again. Then, once you feel confident, having a stoma will not affect your driving ability. However, it is wise to check with your motor insurer as policy conditions can vary. If you find the seat belt is uncomfortable

across your stoma try fitting a "Klunk Klip" device. These can be obtained from most car accessory stores, or on line. The klip is attached to the inertia-reel of the seat belt and reduces the pressure on your colostomy. Forward movement releases the klip allowing the restraint system to operate normally.

Can I travel at home or abroad?

At first it is natural to feel a little apprehensive about how you will cope with your colostomy away from home. Start with a short trip in this country and as your confidence grows venture further afield.

If you are travelling abroad:

- check that your holiday insurance covers pre-existing conditions. A factsheet listing companies providing travel insurance for colostomates is available from CA Head Office.
- remember to pack your stoma supplies (twice as many as you think you will need) in your hand luggage.
- carry a travel certificate (available from CA Head Office) which explains in different languages that you have a stoma and need to carry medical supplies.

Every year many thousands of people with a colostomy travel by road, sea and air – even on long haul flights!

Making the decision to talk about your colostomy

To tell or not to tell? Obviously you will need to involve your partner and you may feel more comfortable telling the rest of your family together. Only you can decide who else you should tell. Some people prefer only their close friends to know. Others are quite happy to tell anyone that they have a stoma. The decision is up to you.

Remember, having a colostomy has not changed who you are. You are still the same person you were before surgery. It may take some time to come to terms with your altered body image. If you would like to talk to someone who has a colostomy call our Helpline 0800 328 4257.

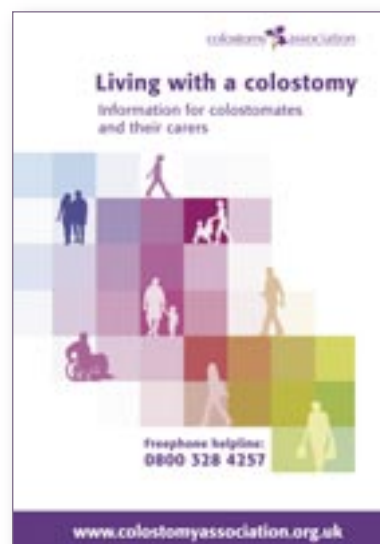
Will it affect my sex life?

Most people with a stoma can enjoy a healthy sex life. It is often the case that the person with the colostomy is more aware of the stoma than their partner. Some colostomates feel more comfortable wearing attractive underwear, use a cummerbund to conceal/support the bag or use a pouch cover. Mini-pouches and stoma caps are also available.

If the rectum is removed during stoma surgery:

- some women may experience a different sensation, pain or dryness in the vagina during intercourse. This can be helped by using a lubricant.
- some men may experience difficulty in getting an erection. However, this can be successfully treated in 90% of cases.

Should you experience any such problems do not be embarrassed to discuss them with your surgeon, GP or stoma care nurse. The Colostomy Association has a number of male and female volunteers who are willing to talk in confidence about any concerns you may have.




The above article is taken from the CA booklet **Living with a colostomy – Information for colostomates and their carers.**

This booklet is available from the CA office or online at: www.colostomyassociation.org.uk




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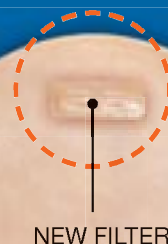
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How to feel good about yourself...



CA Volunteer
Margaret Simister
writes...about 'life'
with a stoma...my
relationship with my
stoma has certainly
changed over the
years - it is now
a familiar friend

This cannot be a 'one size fits all' article because the reasons for having a colostomy our circumstances, lifestyles, general health, finances, age, sex and size will differ. But make no mistake, there is one certainty for all ostomates, that for whatever reason you have a stoma and bag, they are there to help.

So as soon as you are able, (from day one of consciousness in my case), be kind to yourself, your stoma and your bag. Make your stoma your new friend, after all it may, (as in my case), have saved your life, stopped your pain or incontinence - keep reminding yourself of that. I remember I became rather fond of my stoma - much to the amusement of my stoma nurse! (I actually have an ileostomy, which sticks out a bit more than the neat colostomy stoma and watching it in action is truly fascinating sometimes!) Also it helps me to think of the bag as not being part of me - just an aide like a large plaster or hearing aid. The stoma itself is relatively quite small after all.

Initially, your stoma and bag will feature large in your life, but as you recover and get more experienced and confident, this focus will diminish. My relationship with my stoma has certainly changed after nearly five years - it is now a familiar friend which I often take for granted, occasionally find irritating, but mostly forget about until the bag signals it needs changing! No more rushing to find a loo or terrible abdominal pain, (I had bowel cancer and still have Crohn's). And this is the point, you are on a journey of change and if you are determined enough, a road that becomes easier to travel.

What is important to most people (after actually surviving the op of

course) is how they will feel and how they will look with a colostomy. In my view, these two things are mutually dependent, even inseparable and certainly both can affect one's ability to cope.

Body image for example is particularly crucial to today's young when they are attempting to form relationships, living as we are in this image-obsessed age. There certainly have been times when I have looked a lot better than I have felt and vice versa. On a visit to the hospital in the early days, my care nurse commented on how well I looked. Unbeknown to her, I was now knickerless (after forgetting a spare pair) after having an accident on the way there and subsequently having to clean up the public loo. But at least on the outside I had kept up appearances and maintained my dignity even though I felt terribly weak and upset. Other times I have felt great - but looked thin and gaunt. Sometimes you do have to look very hard to find the upside!

Strengthening your pelvic core muscles both pre and post op is good as this will help to avoid developing or worsening a hernia. Wear a support garment from day one of walking about. Don't lift anything to start with. Find the support garment that suits which gives the right amount of support without squeezing the bag. These do not have to be specialist - they can be a version of what you wore before if you are a woman. Initially I was prescribed a very wide hernia belt, but now wear a 1" wide belt that loops onto the pouch of my two-piece bag. I wear this all the time, as I don't want my parastomal hernia to get any bigger! I also wear looser ordinary panties at night just to hold the bag in place.

Dress to disguise! Of course, large hernias can be the most difficult things to conceal. I was 'lucky' in that as it took me so long to recover, my enforced bed rest may have prevented my small hernia worsening. But at least colostomies are hidden and can be disguised by clever dressing. If you are fashion conscious, utilise current fashions to your advantage. Baggy, smocky tops for ladies are in at the moment, as are shirts worn outside trouser for men. A small long handled handbag worn cross-wise resting on the bag is good coverage when the bag swells - often after a meal when you need to exit the restaurant or wherever. For holidays, wear a sarong around a swimsuit or a pretty kaftan or wrap a towel around you whilst walking about. You may be a 'bag lady', but you can be a very smart bag lady!

As you recover, keep up as best you can the personal appearance and grooming standards that you had before. A real tonic is to get someone - a friend perhaps, to wash your hair or give you a manicure if you cannot get out. I wasn't able to get my hair washed for 9 weeks - the upshot was that my normally dry hair was in wonderful condition! Ditto eyelashes. This may sound trivial, but anything that helps you feel more human - a long hot shower, a home foot, hand or body massage will help.

You are definitely not alone if you experience some sort of difficulty or accident whilst you get used to caring for your stoma and using the equipment properly or finding the equipment that suits you. Be prepared is the mantra. Until you have complete confidence in the equipment you use, (and this can take quite some time) always take a spare set of equipment and clothes with you when you go out. I didn't wear light coloured trousers for a long time. Also give yourself extra time to get ready - initially you will need longer to put on your bag - but over time you will speed up. What used to take me up to 20 minutes now takes me five max. When your stoma has settled

down and stabilised probably at a smaller size, get your supplier to pre-cut your bags. Get to know the habits of your stoma and what foods affect the output. If you are a heavy sleeper, set your alarm to wake you to empty your bag so avoiding accidents.

How you cope with your stoma often depends on the circumstances of you having to have it in the first place. Naturally, it is harder and takes more time to adjust psychologically if it has been done after an emergency as you have not only had to get over the sudden op but adjust to having a stoma too. But it is not a competition, listen to yourself and take the time you need to come to terms with your new situation - importantly - talk to others - ask questions. Accept all the appropriate help offered. Often we are so glad to have survived the op we suffer in silence! Don't! There is help out there. Seek It! Do not suffer alone. Do not accept that you have to put up with repeated accidents or inappropriate equipment. Develop coping strategies as you learn from your mistakes. Learn who to contact when things go wrong - and, (and I feel very strongly about this), contact the CA there is nowhere better for non-medical advice - trust me I know, I have worked there as a volunteer for nearly three years and I wish I had known about them before my op, my journey to where I am now would have been much easier.

You are still the same person and this is the life you have been given, so make your choice and LIVE IT!

Margaret Simister

Factsheets and past articles from Tidings Magazine...

A large range of informative factsheets and articles are available on request from the CA office or can be found online: www.colostomyassociation.org.uk

Here are just a few...:-

- Adhesions & Blockages
- Bed Protection
- Beating Bowel Cancer
- Ballooning
- Body Image
- Coping With Chemotherapy & Radiotherapy With A Colostomy
- Coping With A Colostomy & Arthritis
- Coping With A Colostomy & Multiple Sclerosis
- Coping With A Colostomy & Spinal Injury
- Caring With Confidence
- Colitis
- Crohns
- Convexity
- Colostomy Reversal
- Constipation
- Choosing The Right Pouch
- Deodorant
- Disability Rights
- Diarrhoea
- Diet
- Dips & Creases
- Diverticular Disease
- Exercise • Stoma Reversal
- Emergency Surgery
- Seat Belt Protection & Extenders
- Going Into Hospital
- Hints & Tips For New Ostomates
- Incontinence
- IBS
- Irrigation
- Intimacy
- Liking Yourself
- Leakage
- Medical Adhesive Removers
- Medicines & Your Colostomy
- Manufacturers
- Pancaking
- Prolapsed Stoma
- Problematic Stomas
- Parastomal Hernias
- Pregnancy
- Pre Op & New Ostomates
- Returning Home After Surgery
- Regaining Bowel Control



Breakaways latest adventure... and NOT a parent in sight!



For the first time ever, Breakaway took a group of 11-18 year olds away for the weekend without their parents! Our feedback over the years has shown us that as children hit secondary school age, they have a huge desire and need to be independent.

Children with Bowel and Bladder diversions often miss out on the opportunity to have sleep overs at friends houses or go away on residential school trips. Breakaway understands the intricacies and pressures that surround each child and family unit. Lack of understanding from others can influence the confidence levels not only of the child but of the parents too. Subliminal messages may impact on or put a stop to activities that are in essence an essential part of the growing up process. For both parties especially the child learning to manage their medical condition themselves in different circumstances can build confidence and acceptance.

Breakaway knows only too well that children CAN manage on their own and understands that with the right help and support – children CAN gain the confidence to be themselves – independent individuals.

Last October paediatric nurses headed off on what was a very cold weekend to a residential activity centre in Shrewsbury. Twelve children were delivered by their parents – along with sleeping bags, gloves, hats, wash kits and suitcases full to bursting with hair straighteners and midnight feast goodies! Some of these children had never been away from their parents before, so there were understandably a few nerves as the final goodbyes were said.



The children were settled into their rooms....and then the fun began! No one, children or nurses got much sleep the first night but all were up bright and breezy in the morning ready for an action packed weekend!

The weekend included canoeing...and yes despite it being freezing cold they all managed to get soaking wet! Other challenges – a giant swing, assault course, climbing and leap of faith and lots more besides!

The second night was slightly more subdued – the children and nurses all enjoyed a late night feast outside tucked up in sleeping bags eating chocolate. One of the nurses who attended said, 'it was amazing to see the children sat together all snuggled up chatting about things that in their everyday life they cannot talk about.'

That's what makes Breakaway so unique and the event so important! The children bonded together and supported each other throughout the weekend's activities and took team building to another level! Jeni Senior (a children's urology nurse) said, 'it was fantastic how they encouraged each other through their individual fears and conquered them.'

Our volunteer nurses managed stoma bag changes, Mitrofanoff catheters, over night drainage bags, ACE washouts and meds to fit around the activities so that the children didn't miss out on anything.

Children supporting each other (with medical challenges)...where else could this happen? But at a Breakaway event!

Our aim from this event was for the children to gain independence and confidence in dealing with the everyday challenges that living with a stoma throws at them...so, what did the kids say about the weekend?

'I have had a colostomy since I was a baby, sometimes it is hard to go away with friends as they don't really understand. I went to Breakaway without my parents and realised that I can be independent and manage things by myself. I was one of the older kids at the weekend, and it was great to be able to share my experiences and help the younger kids. I talked to them about things that I have already coped with.'

Emily aged 15

'I had a great time at Breakaway, I was a bit scared about going without

Mum and Dad, but once I was there and knew where everything was I was fine, the nurses helped me with my ACE and Mitrofanoff, but I didn't really need them. We had so much fun and we stayed up really late! I wouldn't be scared about going away without Mum and Dad now because I know that I can do it all myself.'

Hannah aged 11

We plan to hold more of these events in 2013* please check out our website for further details.

Julie Bastin
Founder and Trustee

*to be eligible to attend a Breakaway event which doesn't include parents, you must have attended a Breakaway family event prior to this.

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Breakaway NEW events for 2013...
24th - 27th May 2013 at
YHA National Forest

OR
23rd - 26th August 2013 at Woodrow
High House, Cherry Lane, Woodrow,
Amersham, Bucks HP7 0QG

New ostomy study: Leakage and skin irritation significantly reduced through evidence-based nursing

A new global study conducted among 3017 users of ostomy products confirms the correlation between leakage and peristomal skin condition.

The study, which is the largest real-life study within ostomy conducted to date, also shows that leakage and skin irritation can be significantly reduced through evidence-based nursing – a mix of global ostomy tools based on clinical research combined with the stoma nurse's own experiences.

The Global DialogueStudy was carried out in 18 countries around the world and more than 500 nurses were involved in recruiting patients and monitoring and reporting observations and findings. The consolidated data from all 18 countries were presented at a special international event with more than 200 healthcare professionals in attendance.

Janet Stoia Davis, a registered nurse for more than 34 years and an international lecturer on ostomy issues, explains the survey process:

'A clinical study within ostomy typically has around 100 participants or less, so the results of the DialogueStudy, providing data on over 3000 users will

have a tremendous impact. This is the first time we have this many healthcare professionals and users in so many countries involved.'

The 500 nurses involved in the DialogueStudy were all introduced to the use of the Ostomy Skin Tool and Stoma Quality of Life questionnaire, at the beginning of the process.

'The study shows that overall leakage was brought down from 90% to 60% through evidence-based nursing, which means relying on clinical data, on global tools and on stoma care nurse's knowledge and experience to choose the right product and treatment. A drop of 30% is impressive and exciting! By reducing the risk of leakage there is a significant improvement in the quality of life for the users - and as nurses, and especially stoma care nurses, our goal is to have the ostomy fit into the lives of our patients not to let their lives fit around their stoma. The DialogueStudy has provided us with a lot of data to pass on to both our colleagues and individuals living with a stoma.'

The DialogueStudy was carried out by Coloplast, who also hosted the special event at their Danish headquarters.

Coloplast's SenSura® products were part of the study and combined with evidence-based nursing, the SenSura products showed the best results.

According to Janet Stoia Davis, the DialogueStudy is a great example of a supplier of products working together with healthcare professionals in order to provide better care, but she also has a challenge for Coloplast and other suppliers of ostomy products.

'The DialogueStudy shows us the importance of knowledge – the importance of educating nurses on an on-going basis. This approach can decrease leakage significantly; however, the study also shows us that it cannot completely eradicate the risk of leakage. So we also need a continuous focus on product development. People have different body types and therefore different needs, so we need to continuously develop new products to meet these needs.'

To learn more about this study visit:
<http://www.us.coloplast.com/about/news/new-ostomy-study>

How to avoid leakage of your appliance...

Leakage is often due to poor stoma construction, retraction, placement, complications, improper product use or inadequate fitting...

Below are a few of the most common problems, with suggestions for handling them. For further information, always consult your GP or stoma care nurse.

Poor Adherence to Peristomal Skin: Make sure that your peristomal skin is 'dry' before applying your pouch. Hold a warm hand over the pouch and stoma for 30-60 seconds after application, to warm it and assure a good initial seal.

Wrong Size Pouch Opening: If the size of your stoma has changed (due to post-operative shrinkage or change in weight) and you have not re-measured and adapted the opening accordingly, undermining of the wafer and leakage may result.

Folds or Creases: If folds or creases develop in the skin, and leakage occurs along the crease, wafer pieces or ostomy paste can be used to build up the area in order to avoid leakage. Consult your stoma care nurse for proper methods.

Peristomal Skin Irritation: Pouches will not stick well to irritated skin. So, perform meticulous skin care in order to avoid irritated or denuded skin. If any of these problems develop, consult your GP or stoma care nurse at once, so that the problem can be addressed.

Improper Pouch Angle: If the pouch does not hang vertically, the weight of its contents can exercise an uneven twisting pull on the wafer and cause leakage. Colostomates must find an optimal angle based on their individual body configuration.

Too Infrequent Emptying: Pouches should be emptied before they

become half full. If they are allowed to overfill, the weight of the output may break the seal and cause leakage.

Extremely High Temperatures: Wafer melt may cause leakage in warm weather.

Pouch Wear and Tear: Disposable wafers wear out. If you are stretching your wear time, leakage may be due to the wafer wearing out. Change your appliance more frequently.

Ageing product: Store your ostomy supplies in a cool dry place, humidity may affect your pouch adhesive. Appliances don't last forever. Ask your supplier what the recommended shelf life is for your brand of pouch. Keep some extra pouches on hand.

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Are you having problems with your Prescription?

The Colostomy Association is aware of an increase in the level of calls and emails around fulfilment of prescriptions - particularly relating to GP surgeries/Pharmacists. To help us understand more about this activity we would appreciate your help!

Please fill in the form opposite and list any experiences or problems you have recently encountered when ordering your prescription or repeat prescription such as queries over levels of appliance supply or queries over types of product e.g. adhesive sprays etc.

Thank you

Please **complete the form below** listing any experiences or problems you have recently encountered when ordering your **prescription/repeat prescription**. Then simply return by **post** to the **The Editor, Colostomy Association, 2 London Court, East Street, Reading, Berks RG1 4QL**. Telephone: **0118 939 1537** if you have any queries.

Title: _____

Name: _____

Address: _____

Postcode: _____

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I have encountered to following...

Please continue on a separate sheet if necessary and attach to this form.

Data protection: The information you supply will be used by the Colostomy Association for administrative purposes within the terms of the Data Protection Act 1998. We shall not supply it to third parties and your information will be held securely.
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Dear Nurse

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

Q: *I have a colostomy, which was as a result of Diverticulitis. I'm not sure if I can have a reversal but would like to know how it is decided. Can you tell me what the procedure might be and who to ask? Many thanks.*

A: Reversal of stomas are possible in certain instances, which obviously vary from individual to individual. I would recommend discussing the potential with your surgeon who will be able to decide if this is a suitable option for yourself dependant on the original surgery and with consultation with yourself. You don't say if the stoma is an end or a loop colostomy or if the original surgery was done as open or laparoscopic (keyhole) surgery. This may have an impact on how the surgery is performed and again your surgeon can help with this. Reversal of stomas is a fairly fast procedure and many people find they are not in hospital for a long period following this. However some people do experience erratic bowel habit for a period following surgery, although this often settles and people manage well.

Good luck and all the best for any decisions you make.

Q: *I am at my wits end and don't know what to do for the best. I have what seems like small ulcers on my skin around my stoma and don't know why they are there. I can't seem to get on with my stoma care nurse and my GP doesn't even want to look at my stoma. Can you please advise me on what to do – I'm really upset.*

A: I'm sorry that you feel you are unable to get any help from your Stoma Care Nurse or GP. There are many reasons why you could get



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.

'ulcers' around the stoma. They may be due to trauma from the products you are using, excoriation from the output if the template in the pouch is too large, medications such as Nicorandil or a skin condition known as Pyoderma Gangrenosum. You will require a review to decide what the actual cause is and I would recommend a review by your Stoma Care Nurse. All of these causes are treatable but you will require a Health Care Professional to see you. If the cause is identified as being Nicorandil you will need a medical review to ensure the medication is replaced with an alternative and treatment for Pyoderma requires medical support

too. The others are fairly easy to treat with the use of accessory products or a change in pouch, but again a review will be needed to identify the actual cause and ensure the correct treatment plan is decided. I hope you find a solution to your problems with support from a Health Care Professional.

Q: *My husband had a colostomy about eight weeks ago and has recovered well. The problem causing concern is 'wind'. We have read several leaflets together explaining what not to eat but cannot find any suggestions on what is suitable. Please could you give us a few suggestions? As we mainly eat vegetarian meals. Thank you.*

A: Flatus or 'wind' is a common issue especially in the early days and you may find that it settles over a period of time. It is often related to certain foods and by keeping a food diary you may be able to identify the problematic foods. You can then choose to avoid these foods or be aware that they will cause wind when eaten. Some patients find that using things such as peppermint (mints, cordial or tea), fennel (vegetable, mints or tea) and charcoal (tablets or biscuits) help. Hopefully these ideas will be of some use to you.

Q: *I have a problem with my stoma it appears to be what I can only explain as 'falling out'. I contacted the duty doctor at my local hospital and he advised me to lie down and said that it would retract – which it did – whilst I was lying down but then when I got up – it happened again. Is this normal? It's very worrying – can you advise me as to what I should do about it and what might be causing my stoma to behave like this.*

A: This sounds like a prolapse. You are correct that if you lie down the stoma will retract and be flat but as you found out when you stand up again it will prolapse back out. As long as the stoma is healthy and acting and the pouches are remaining intact and not leaking then it is

manageable with help from your Stoma Care Nurse. They will be able to advise you as to what products will help with managing the problem and what to observe for and when to seek further help. If the stoma prolapse is causing problems for you then it would be worth speaking to your surgeon who may be able to offer a specialist support belt to help or even a surgical solution to the problem.

Q: *I am really worried about my husband. He had his colostomy about 15 months ago and up until now things seemed fine. Recently he has become very depressed. He is experiencing leakage from his bag – I don't understand why this is happening and I don't think he does. Please can you help? Yours in anticipation.*

A: Leakage from your pouch is very distressing, especially if it is continuous and causing sore skin. This may be the reason why your husband has become depressed. There are many reasons why a pouch can leak and most of them are easily solved with the use of accessory products, a change in template or a change of pouch type. If we can help to prevent the leakages then over time he will hopefully regain his confidence. I would suggest a review by his Stoma Care Nurse as soon as possible so that they can assess the stoma and identify the potential problem causing the leaks. Once the problem has been identified then a treatment plan should be developed to improve matters for him.

Q: *My mother had a colostomy earlier this year. She is quite elderly and has been diagnosed as suffering with dementia. She keeps removing her bags and I don't know how to resolve this – is there anything you can suggest – that could help me to help her.*

A: This is a problem we have encountered ourselves and can be very hard to manage. If possible and the dementia is not too bad repeatedly explaining that the pouch must be left intact can help. Alternatively, using clothes, which can be fastened so that access to the pouch is not possible, can deny access to the pouch for your mother. There are many different products available and some such as the Microskin (Oakmed) have very thin adhesives and this can make it more difficult for the patient to remove the pouch. A review by the Stoma Care Nurse will help provide support for both yourself and your mother.

Q: *I am a new colostomate and need some advice about bathing. When I have my bath which is usually in the morning my pouch comes off in the water. Can you please advise as to what I should do? Is there a procedure I should follow? All information is gratefully received. Many thanks.*

A: Pouches should be able to be left intact whilst you bath, shower or even swim in them so I don't understand why the product you are wearing is coming off. It may be worth seeing your Stoma Care Nurse who will be able to help identify the problem and find a solution. I do have patients who remove the pouch to bath or shower, although the stoma may work without warning and if you are in the bath obviously the stool is in the water with you. In the shower the output would be washed into the drain so is not so much of a problem. Obviously pouches leaking when in water would prevent you using a swimming pool and therefore the problem needs to be solved.

Q: *I have had my colostomy for nearly 14 months. Recently I have had very little output and what I do have is hard. I have been to see my GP who suggested Lactulose but I am worried that I may become dependent on it. Could you advise as to what I can do to loosen my output.*

A: It certainly sounds like your stool is constipated. A colostomy does not need to work daily, it is acceptable to work every 2-3 days but I would not suggest leaving a stoma with no action for longer than 3 days. Also if the stoma output is hard as you describe then altering your diet may help. Increasing the amount of fluid you drink to approximately 10 cups/glasses per day and increasing the food groups that help bowel movements, such as foods with fibre and fruit and vegetables may help. Certainly the use of laxative, such as Lactulose, Senna, Fybogel as well as others can help. Some patients only require these short term but other patients use them for longer periods. You need to be guided by your GP or Pharmacist as to the frequency and length of time to take them and then you should not have any problems.

What kind of stoma do you have?

When food leaves the stomach it enters the small intestine, a long coiled 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 as necessary.

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 right 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:
editor@colostomyassociation.org.uk

The saga of two boxes...

At the beginning of last November I was called by my DAC to place my November order. This would be delivered around about the 25th of the month. I was told that although my December order would be taken in early December this would not be delivered until January and so it might be an idea to order enough supplies to cover the Christmas period. I normally have five boxes of pouches and this was increased by two boxes to make seven boxes in all.

About a week later the DAC called me to say that their request for the prescription which included the two extra boxes had been refused and the surgery had made the prescription out for the five boxes as normal.

Naturally this apparent action by the surgery infuriated me and caused great concern. I had never been refused before and so letters and emails were sent to the GP, the Practice Manager and to the DAC.

The DAC responded immediately by saying that they would sort this out. Why had they not sorted this out before calling me to tell me about the refusal of the order for the extra two boxes?

The DAC then returned to say they had spoken with the practice and it appeared that someone at the practice had not spotted the reason for the extra two boxes as this was written on a compliments slip and not on the actual order. Perhaps we had to assume that the person at the surgery thought the seven box request was a mistake as my order is normally five boxes and so they corrected it.

Actually the order was very different from my usual as it did not have any flanges on it or sprays or SkinSafe wipes. I haven't received the order so I don't know if these have been added back in. The DAC did admit that they could have been clearer about explaining why the order included two extra boxes of pouches.

The surgery have since written me a letter saying that the DAC called them and it appeared that there had been a breakdown in communication but that they understood that there was no error made at the surgery.

So the DAC while suggesting that they could have made the order clearer, do feel that the fault lies with the surgery and the surgery feel the fault lies with the DAC. One of them is correct, but which one?

As an ostomate one is helpless. The power that a GP wields over us is enormous. One stroke of the pen can turn our lives from acceptable into miserable. I have been fortunate to date I have been well looked after by my doctor and the surgery over the last 18 years and through some pretty heavy stuff in the last 6 years, during which they have never let me down and I am relieved to think it might not be their fault. Good GPs and good surgeries are hard to come by. DACs on the other hand are in plentiful supply.

But as we have two different stories, I went back to the DAC to let them know what the surgery had said. The DAC called me and they will be speaking to the surgery again. As I said that is up to them. Wherever the fault lay in all this there is one inescapable fact and that is that having suggested that I increase the size of my order the DAC once they had been refused the two extra boxes did not sort the problem out. They simply called me to tell me that the order had been refused.

The NHS is supposed to put the patient at the heart of the issue. If the DAC had put the patient at the heart of this issue they would not have troubled and worried the patient with their news but would have done their level best to sort the matter. The patient would frankly rather have been unaware of the goings on than been alarmed as he was. It would have been much better for the

patient/surgery/GP relationship if the patient had known nothing of the changing of the order and the relationship with the DAC would have remained excellent, too. As it is by not sorting this out and by involving the patient the DAC have dented their relationship with the patient and harmed the patient's relationship with the surgery/GP which is much more important.

If you are not an ostomate you cannot understand. I think everyone who works in the stoma business should be locked in a room for a week with no lavatory. They should then be fed a great deal of food. At the end of the week they would understand the fear that never leaves an ostomate, the fear that drives our lives however well we manage. Do we ever leave the house without a spare bag in our pocket. You bet we don't.

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Top hints and tips for colostomates...

- Make sure your peristomal skin (the skin around the stoma) is completely 'dry' before applying the flange. Bathrooms can be warm and humid after a bath or shower so give your skin plenty of time to dry thoroughly.
- A few drops of pouch lubricant inside the top of the appliance will help prevent 'pancaking' of stool around the stoma. Most of the stoma product manufacturers or suppliers make such lubricants – ask for a sample.
- Use two hands to remove a flange, one to hold the skin down and the other to gently peel the flange away. Try to minimize how much you are stretching or pulling on the skin.
- Write the day you change your appliance in indelible ink on the outside of the barrier itself to help you remember when it's time to change again, or better still keep a calendar in the bathroom for this purpose.
- If your paste tube has become too hard to squeeze, put it in a glass of hot water for 20 minutes and it will become more malleable
- If you are being admitted to hospital for tests or any other reason, take your own ostomy supplies with you! The hospital may not stock what meets your particular needs, or attending nurses may not be familiar with ostomies. Even if the hospital has what you require, it may take a bit of time to locate it.
- If shaving abdominal hair, use an empty cardboard toilet roll as a shield around the stoma. Shave in the direction of hair growth.
- Oatmeal added to your bath can relieve itchy skin. Pour some oatmeal into a cloth bag or a piece of cheesecloth, tie it shut and put it into the bathwater.
- If you use skin sealant, make sure it dries completely before applying the flange.
- Pay attention to skin problems - address any signs of skin irritation immediately. If you're not sure what to do, call your stoma care nurse.
- Don't let the pouch get full before emptying. Excess weight will separate a two-piece system and will also put too much weight on the skin barrier resulting possibly in multiple problems. Empty the pouch when it is about one-third full, or sooner.
- An ostomy belt can help keep your appliance secure if you're having trouble keeping it in place.
- For ladies that have become enlarged around the abdomen and find that wearing normal tights is unbearable, try wearing maternity tights. They are more comfortable.
- Keep your ostomy supplies in a rolling cart with 3 drawers in your bathroom along with a list of your supplies and their reference numbers it's handy for reordering or taking with you if you need to go into hospital.
- If you are changing the flange etc., with your clothes on, roll up your shirt/sweater at the front to reveal the ostomy. Then take a clothes peg and peg your clothes out of the way. This way you have both hands free to clean your ostomy, and will not have to struggle with one hand as the other is holding your clothes up, or worse yet saves you getting chin/neck ache from holding the clothes up with your chin.
- In cool weather it can be helpful to warm the back plate under your arm or on a warm radiator for a few minutes to allow it to soften up, which in turn makes it easier to mould to your abdomen.
- Take your time to chew food thoroughly, don't swallow large lumps. This not only helps the stoma to deal with what will eventually go through it, but can make meal times more enjoyable and relaxing.
- When travelling, take twice the normal number of flanges and pouches you would normally expect to use. As changes in food and activity levels can disrupt your normal routine.
- If you have uneven or hollows in the skin around the stoma this can be a potential leakage area as the back plate will not get full adhesion to your abdomen, Try a small amount of 'Stoma Paste' in the hollows before fitting the back plate.
- Try not to eat a large meal late in the evening. This can cause the pouch fill more quickly overnight, and disturb your sleep as it will need emptying. Depending on the type of stoma you have the time food remains in your body will be somewhat reduced.
- Pain Killers – if they contain codeine this may cause the stool to become harder/constipated. Make sure to drink plenty of water.
- Try tips from other ostomates that might apply to issues you have but remember everyone is different. What works for one person may not work for another but it's worth a try.
- Perhaps the most important bit of advice is don't get down on yourself if you make mistakes! We've all made mistakes and sometimes we still do. Learn from any errors you may make and keep moving forward.

If you have a top hint or tip please send it in to the Editor either by letter or email. Please go to page 6 for details on how to contact the Editor.



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Supporting you everyday

Readers' writes

We want to hear from you...learn about your experiences, understand your concerns, read your hints and tips...so write, email or phone the Editor today!

Dear Editor

I have had my ileostomy now for 2 1/2 years and by and large experience few problems (thankfully). I am saddened to read the letters from others who have had problems with GPs and prescriptions as my supplies come direct without needing a prescription each time around and in fact I have had extra items added without query (additional adhesive tape being one regular item).

I have two questions which I would like to pose for general discussion:

1) when applying for jobs, as I have been for the last year or more now, do readers feel that they should tick the disability box or not? Sometimes I do, other times I do not because I feel that my condition is more of an inconvenience than a full disability, but I wonder what others think.

2) From a confidence point of view, I have not engaged in any sporting activities since my operation - I understand that the appliances are guaranteed water resistant, but I would not like to test this out and be "caught out" in a public environment for any number of reasons, so has anyone experience (good or bad) relating to this? I have tried contacting my local disabled swimming group but have had no reply thus far.

Yours,
N.A

Dear Editor

For a number of years, I've had an inverted stoma. This has given me many embarrassing leaks and much laundry over the recent years. My stoma care nurse recently introduced me to Pelican convex and their 'rings' - I change every three to four days and occasionally have the odd accident and am now content!

Regards,
WDW

Dear Editor

I requested Hydroframes - the doctors surgery telephoned me to ask what these were and why did I require them. I had to explain I'd had an accident with my wafer and bag and these frames gave extra security. I felt embarrassed having to explain this. I have had a colostomy for nearly 21 years and I have never requested anything that I don't use. I did receive the prescription with the Hydroframes on but not on the repeat prescription.

Yours sincerely,
J.S

Dear Editor

I have had trouble obtaining my colostomy bags from my doctors. My stoma care nurse requested a prescription for 4 boxes of colostomy bags per month. My husband picked up my prescription from our doctor. It was for 2 boxes per month. He was told it was because they were "high value items". My stoma care nurse then tried to contact the doctors but he was met by the same result as my husband had been - they could not get past the receptionist. The nurse then sent a further request, I assume saying that this was causing me a great deal of stress. I was then given another prescription for 4 boxes of bags.

This did cause me so much stress that for a week - until it was sorted - I could not eat, causing me to use less bags. When I mentioned this to the nurse, his immediate response was that we may be able to cut back on the quantity of bags requested.

As I am now back to eating and going through bags at a higher rate, I am now very afraid that I may be faced with this dilemma all over again. Also, the nurse told me that the only supplies I could be supplied with by the NHS were the colostomy bags and 2 aerosol of remover. He told me to use kitchen roll to clean myself and nappy bags for disposal of used colostomy bags. He said I did not need stoma powder or any other products. People at the Hull support group say I should have more. I do not know!

Yours in anticipation
V.M. W

Dear Editor

I have had my colostomy spray stopped which I find very embarrassing when I am in company. The smell at times is terrible, now that they have stopped the spray it is even worse, no-one asked to have a colostomy and these people who have stopped the spray should live with what I have.

Yours faithfully,
C.R.N

Readers' writes

Dear Editor

I read every Tidings magazine form cover to cover and have found the advice given invaluable.

I was operated on for bowel cancer in 2004. At the time I did not expect to have a colostomy, but unfortunately, four days after the removal of the tumour, I developed a virginal fistular and was rushed to the operating theatre to be given a stoma. After that I received chemotherapy and radiotherapy.

In 2006 I was operated on for a parastomal hernia and a mesh installed. In 2007, because I had suffered bouts of frequent vomiting and extreme abdominal pain, it was decided that I had lower intestinal adhesions and these had to be released as they were causing partial blockages. After this operation my digestive system took a tum for the worse, but I was advised that apart from changing to a diet prescribed for IBS sufferers, there was not much else that could be done.

In 2011, the mesh became infected through a small abdominal wound that I had coped with since the operation for adhesion removal. My surgeon tried her best to remove the mesh in its entirety but could not remove the mesh around the stoma as it had stuck fmnlly to the bowel in that area, so it was decided to leave it and see what happened.

Since then I have suffered continuous bouts of nausea, feeling very lethargic and generally unhealthy. I read the article in the summer issue of Tidings about Dr Andreyev and his team. I asked my GP if I could be referred to a gastroentologist to see if my situation was anything like that described in the article.

I saw Dr Smith at Southampton General Hospital and he told me he has many cancer patients who suffer the same problems, and told me that the small bowel was enlarged and therefore was not functioning correctly and harbouring bacteria that were not supposed to be there. He has prescribed a specific antibiotic which I am confident will help, as in Derek Baker's situation. I have not been put on a special diet, but will pursue this if the antibiotic does not sort out my problem.

My husband has suffered radiotherapy side effects after being treated for prostate cancer and he saw Dr Smith at the same time. He has been advised to take the same antibiotic and hopes that the flatulence and incontinence he suffers, will be greatly reduced.

We are both extremely grateful for the article by Dr Andreyev, and hope that others who suffer from the same problems may be helped as well.

Thank you for your continuing support and very interesting articles.

Yours faithfully,
P.M

Dear Editor

I live in a rural area in Speyside and I am unable to access information as I do not have a computer. It was therefore inspiring to read the article by Sue Hatton on irrigation in issue 25 of 'Tidings'.

I had a recto-vaginal fistula and had a Hartmann's procedure in July 2007 and I returned to the hospital in the December for a re-connection. Unfortunately things did not go according to plan, principally because of adhesions, so that I came home with my stoma as a

permanent fixture together with a pacemaker. When I read the letter in the body of the article by 'OS' I realised I was not too old to try irrigation so I telephoned the hospital and asked for an appointment with a stoma care nurse, having been dogged by constipation and having to cope with the resultant overflow of the backlog at the most inappropriate times!!!

I started to irrigate on the 4th of June very successfully and now find that every other day is sufficient. Irrigation has given me back my life and I am now more confident and have more energy. The joy of once more sleeping on my tummy is just magic. It is also good to find my pouch is a flat pack in the morning and I am no longer afraid to move the duvet in case I should begin to levitate. I really do not understand why irrigation is not promoted more by the hospital or the GP Practice. It would be a saving to the NHS, one feels fresher there is less skin irritation and less pollution.

Yours sincerely,
J.T

Dear Editor

I had Ileostomy 12 months ago and a Proctectomy 4 weeks ago. The only problem that I have had was on the first visit to the hospital. I was released with a serious bladder infection the drugs that I was given were 'coated' and as such passed directly into the pouch without taking effect. This was resolved by the stoma nurses and I am now prescribed liquid drugs when necessary. I have nothing but praise for all of the services that I have encountered.

Regards,
J.D

Readers' writes

Dear Editor

Following your article about diet in Autumn Tidings, I thought I would contribute this in the hope that it will be helpful.

I've had a stoma for nearly four years because of diverticular disease and have not had the reversal through choice. We live in Yorkshire and often travel by train to London and sometimes to the continent. I now have a system which has worked really well to ensure a quiet day when we are on the train.

I start five days in advance, so if we're leaving on Friday, on Monday and Tuesday I eat lots of high fibre foods. We like lentils and chickpeas anyway, so I have them and plenty of fruit etc. This means that by Wednesday 'Hector' (my stoma) is very busy and produces a lot of output. My diet on the Wednesday and Thursday is relatively low fibre. Not completely, though I still have lots of salad and vegetables as usual, but for protein I take meat, cheese and eggs. The end result is that the system has a good clear-out because of the Monday and Tuesday diet, and is slowed down because of the Wednesday and Thursday diet. So on Friday I can forget about 'Hector' altogether. So far it's always worked.

Yours sincerely,
P.T

Dear Editor

I would just like to tell you a success story about accessible toilets. My husband and I were shopping in our local Tesco when disaster struck!

I have had a colostomy for just over a year and I am still very new to it all. This was the first time I had such a bad accident in a public place – the bag just burst. I got to the accessible toilet, and eventually sorted myself out but I realised I couldn't leave the store as I was – I couldn't wear my own trousers due to the accident. So I pulled the alarm cord.

The response was immediate a man was at the door immediately asking if I was all right. 'Yes!' I said 'but I do need a First Aider'. She came along and I explained I had a colostomy that had misbehaved and that I needed some help. She went away and got me some trousers from the clothing department, extra carrier bags and some tissues etc.

By this time my husband had done the rest of the shopping and gone through the checkout and was a bit worried as I was still missing. He enquired as to where I was and was assured that I was being well looked after. We both left the store with our shopping with me very secure in my new clothes!

Thank you Tesco!

Yours sincerely,
F.T

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.

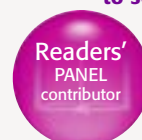
If you want to be involved in the next issue of Tidings magazine simply drop us a line

via email:
editor@colostomyassociation.org.uk

or write to:
The Editor

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

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





Donation Form

The Colostomy Association is an independent charity financed solely by donations. Your help and support is now more important than ever in this changing world...

Our findings show there are approximately 60,000 colostomates living in the UK and with over 6,400 permanent colostomy operations being performed each year - we need to be here for them!

Here's how **your donation helps us** make a difference...to fellow colostomates

We provide:

- **An Outreach Programme** CA's own Open Day event for ostomates.
- **Advisory literature**, written by colostomates and health care professionals.
- **A quarterly magazine 'Tidings'** especially written for colostomates, their families and their carers.
- **A telephone helpline 0800 328 4257** manned 24/7 365 days a year!
- **Around a hundred contact volunteers cover the UK** fully trained and experienced, (who are ostomates) these dedicated individuals bring a human touch.
- **Patient visiting** a volunteer at the request of a stoma care nurse can visit a patient/s before their colostomy surgery, and afterwards in hospital. Home visits can also be arranged.
- **Attendance at organised stoma care nurses 'open days'**, that you can visit and where you can learn more about your stoma, in a friendly atmosphere and discuss any problems.
- **Attendance at manufacturers' and suppliers', 'open days' and exhibitions.** This allows us to update you on stoma care products, accessories and services via 'Tidings'. Display our literature and chat to ostomates.
- **A voice for your opinions at ongoing consultations with the National Health Service** keeping you informed of issues that may affect you.

Here's how **YOU can continue to support us...** simply by making a donation you will ensure our survival...here's how

- **Regular Donation:** Regular donations can be made via standing order (see Donation Form overleaf). Regular donations help us to plan ahead and carry out our agenda. Every donation is vital to the charity's survival.
- **Single Donation:** Single donations from individuals, fundraising events are very welcome and greatly appreciated. So please keep them coming, no matter how small. Just £15.00 (or more) will help cover the cost of all our patient services.
- **Donate via Telephone or online via our Website:** These donations are easy to make...and are secure. Telephone donations are via RBS WorldPay simply call the Colostomy Association office during working hours to donate. To donate online visit: www.colostomyassociation.org.uk
- **Legacy donation - A gift in your will:** If you are about to make a will, or are considering making a change to your current will, please consider leaving a legacy to the Colostomy Association. Your legacy could secure the Association's future and provide continued support to all those 'living with a colostomy' present and in the future.

The Colostomy Association continues... with YOUR help, to give support and reassurance to both experienced colostomates and those who are new to 'living with a colostomy'.

Your donation to the Colostomy Association...will mean we can reach out to other colostomates their families and their carers with support, reassurance and encouragement. With your help we really can and do make a difference - thank you

Please turn this page to donate today Thank you...



Donation & Standing Order Form

Thank you for your support



Please use this form to make either a **Regular donation** by **Banker's Standing Order** or **Single donation**. Simply **complete this form** and return by **post** to the **Colostomy Association 2 London Court, East Street, Reading, Berks RG1 4QL**. Telephone: **0118 939 1537** if you have any queries.

Note: Please ensure that we have your correct details: full name, address and postal code thank you	My Details: Title:	Name:	Surname:
	Address:		
			Postcode:
	Telephone number:		Email:
	Optional Information: Date of Birth:		Reason for your stoma:
Stoma Type: (Please tick) Colostomy <input type="checkbox"/> Ileostomy <input type="checkbox"/> Urostomy <input type="checkbox"/> (NB: The optional information is not mandatory but will help the CA learn more about you – it will not be passed on to third parties)			

1 Regular donation: I would like to make a **regular contribution** to the **Colostomy Association** every **month/quarter/year** in support of the charity. I have ticked the appropriate box below and filled in the amount. I have also completed the **Banker's Standing Order Form** ☐ (Please tick.)

☐ Yes, I would like to make a regular donation of £ ☐ **Monthly** ☐ **Quarterly** ☐ **Yearly**
 (Please tick.) (Important: Please tick your preference above.)

Instruction to your Bank/Building Society to pay by Banker's Standing Order

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Name(s) of Account holder(s):

Account number:

Sort code:

Please pay: **NatWest Bank Market Place Reading Branch 13 Market Place RG1 2EP**

Account name: **C.A. Ltd**

Account No: **88781909**

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Date: / / 2013

2 Single donation: (a donation of £15 or more will help cover the cost of all our patient services)

☐ (Please tick.) **Yes I would like to make a single donation** - My donation is £

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Thanks to the gift aid scheme - we can reclaim money on your donation from the government. **For every pound you give us, we can claim an extra 25p.** For example, a donation of **£15 becomes £18.75 with gift aid**, at no extra cost to you.

☐ I would like the tax to be reclaimed on any eligible donations that I have ever made or will make to the Colostomy Association until further notice. I confirm that I pay an amount of income tax and/or capital gains tax at least equal to the tax that the Colostomy Association reclaims on my donation in the appropriate year (currently 25p for every £1 donated).

Thank you for your gift

Signature:

Date: / / 2013



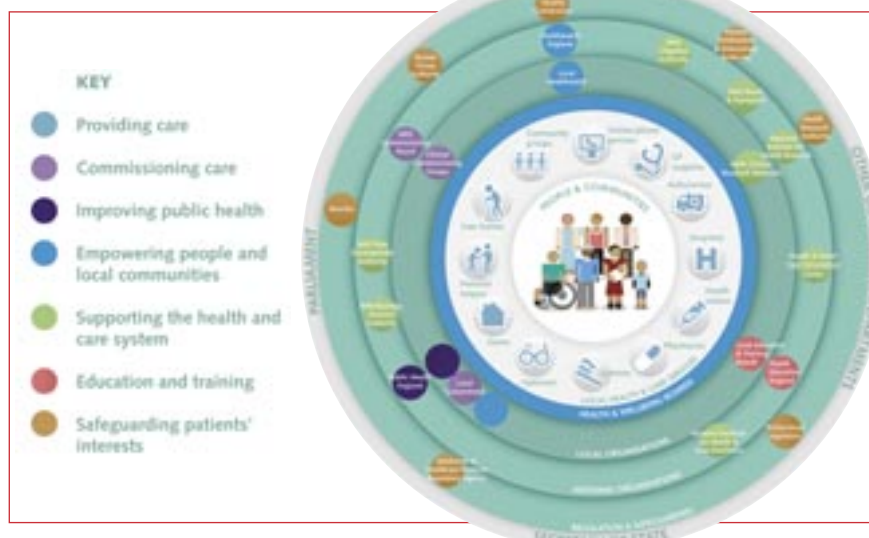
A new type of home delivery service for a brave new world?

This year has been a challenging one for the NHS and for us as its patients. As you will have heard, the NHS is facing the most radical change in its long and varied history, alongside an extremely tough economic situation being faced in the UK. More than ever, the NHS is facing the challenge of providing high quality care to more people and an aging population, whilst having to make cost savings at every turn.

The new health reform bill that was brought into law last year will see some radical transformations to the structure and ethos of the health service. From 1st April this year, Primary Care Trusts (PCT's) – the bodies responsible for providing health and social care services to patients in the community – will no longer exist. Instead, these services will be commissioned and provided by Clinical Commissioning Groups or CCG's, collectives of GP's and commissioners responsible for care in both hospitals and community. With these changes, we will in essence see GP's as budget-holders, tasked with making the most of the resources in a local area, and under great pressure to make decisions that provide high quality and cost-effective healthcare for patients.

At the heart of the 'new' NHS are some fundamental aims and goals. The patient should be at the heart of all healthcare decisions, with informed consent about their care being the rule rather than the exception, and choice being open and fair. Furthermore, a positive patient experience and improved quality of life will be the marker of success, rather than a secondary consideration. With the increase in long-term conditions such as diabetes, there is extra focus on preventative care as well as improving the care of people already suffering from such issues.

With all this in mind – the success of the NHS reforms are a work in progress – how will this impact on such areas as stoma care? Health service changes highlight some areas that are particularly relevant to stoma care: having informed choice around products and services, providing high quality services and improving the



experience of the end user, stand out as three important ones. A new type of prescription home delivery service was created last year to focus on these very things.

Patient Choice is the brainchild of Neil Basil, a patient himself, who through his years of experience in receiving products from various home delivery companies, decided that more could be done to improve the quality of service for end users. The company is unique in the stoma care market, as the only prescription home delivery service dedicated to funding charitable activities. As a not-for-profit business Patient Choice does not have shareholders, but instead supports charities and associations through the money it makes.

First and foremost Patient Choice has been created to provide a high quality home delivery service to patients and offers all of the compulsory services and more, such as a appliance cutting, repeat prescription collection, emergency deliveries in the UK or abroad, sampling service and essential wipes and disposal bags. However, Patient Choice has one further benefit to its clients. The company is not a product manufacturer and is completely independent of any manufacturer, meaning that it is totally impartial and will not recommend any product over another, whilst it can supply any product that is prescribed to a client. Furthermore, accessories are only supplied when they are specifically requested, to cut down on

unnecessary and unused products being forced on patients and wasting valuable NHS resources.

With the growing focus of the NHS on eliminating wastage and overspend, Patient Choice also has a strong drive to help the health service to achieve these aims. Its commitment to reducing waste and saving the NHS money can be seen in its support of the Ostomy Aid project, which was created by Ostomy Lifestyle to redistribute unused products to developing countries (for more information please visit www.ostomyaid.org).

As we head towards April when the planned NHS changes will become a reality, the stoma care market needs to be reflective of the goals and ambitions of the new health service. In Patient Choice, Ostomates will see an organisation created with patients at its very heart, determined to bring choice, quality and a sense of social good to our changing society.

For more information on Patient Choice's new home delivery service or the Patient Choice Foundation, please contact us on 01702 680122, email admin@patientchoicefoundation.org or visit our new website at www.patientchoicefoundation.org.

Nick Howard
Interim Sales & Marketing Manager
Patient Choice

Marketplace

advertise...your events •
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Mid Devon Ostomy Group Advance notice

The Boniface Centre, Crediton is booked for meetings for Crediton Support Group the 3rd Saturday 2-4 every as follows:-

- January 19th 2013
- April 20th 2013
- July 20th 2013
- October 19th 2013

Contact Janice Parkyn via CA
at cass@colostomyassociation.org.uk

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contact: editor@colostomyassociation.org.uk

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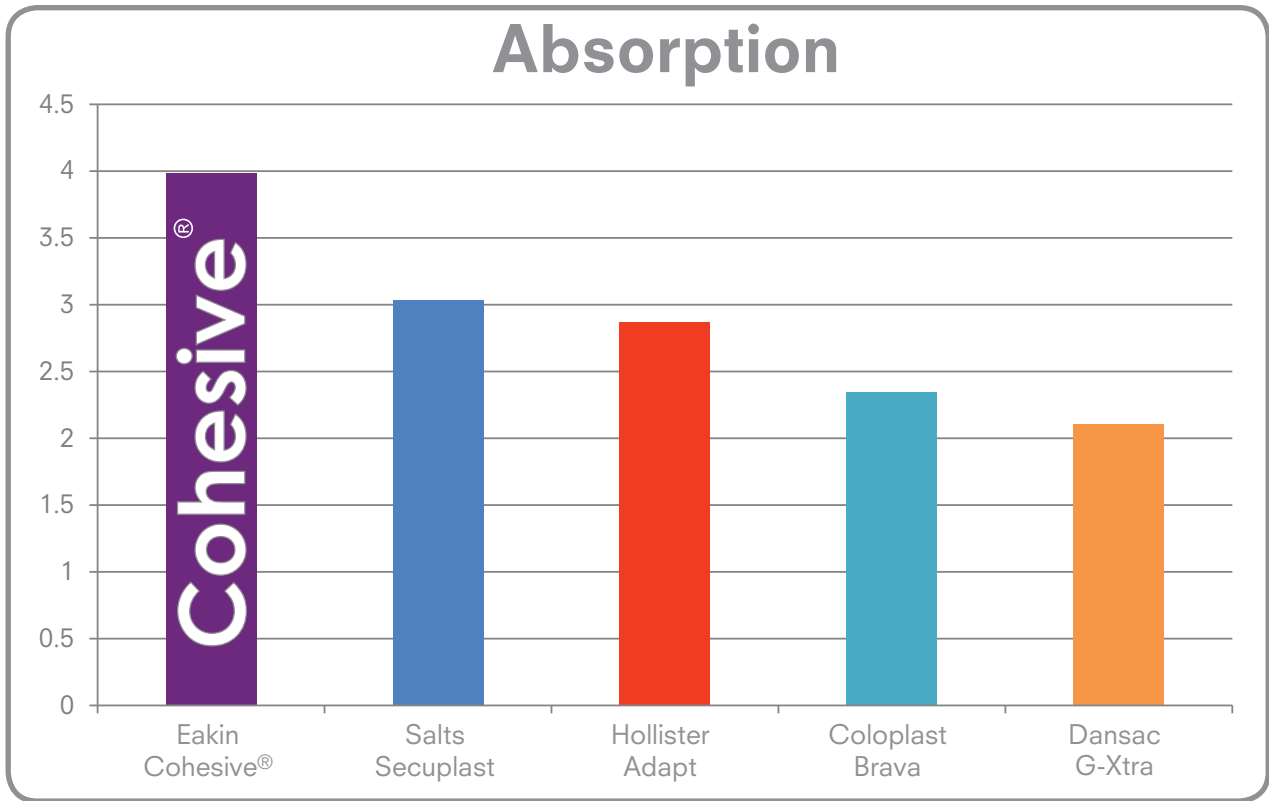


For further information please contact:

Ursula Naish, 9 Oast Meadow, Willesborough, Ashford, Kent TN24 0AS
Tel: 01233 640 863 Email: ursulanaish620@btinternet.com

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HEALTHCARE

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
- 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
- Beating Bowel Cancer UK
Tel: 08450 719300 (Lo Call rate)
Web: www.beatingbowelcancer.org
- Gay & Lesbian Ostomates (GLO)
(The United Ostomy Association in 1982 established the Gay and Lesbian Concerns Committee, now called Gay and Lesbian Ostomates (GLO) Network.)
Web: www.glo-uoa.org
- Ostomy Lifestyle
Tel: 0118 324 0069
Email: admin@ostomylifestyle.org
Web: www.ostomylifestyle.org

Stoma Care Patient Open Day event dates...

A selection of dates will follow in the next issue.

More detailed listings are posted on the Colostomy Association website throughout the year...

visit: www.colostomyassociation.org.uk

SASH

Stoma Support and Hernia Belt

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



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

Ref. no. HB102

Freephone 0800 389 3111

Website:- www.sashstomabelts.com

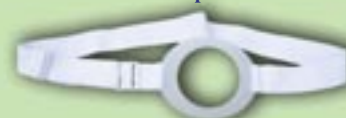
SASH

- Sash belts are available on prescription for a Colostomy, Ileostomy or Urostomy and suitable for both male and female.
- All belts are custom made from information given on the enclosed Order Form. A hole will be cut into the belt flange to fit the pouch you normally use.
- No fittings are required. Belts are processed and mailed within two working days.
- For further information call Freephone : 0800 389 3111 or visit our website: www.sashstomabelts.com

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



"the ring of confidence"

- This lightweight unobtrusive belt is designed to help eliminate leakage problems by holding the adhesive section of the pouch against the body during all activities.
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Ref. no. SR103

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WATCH IT WORK



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

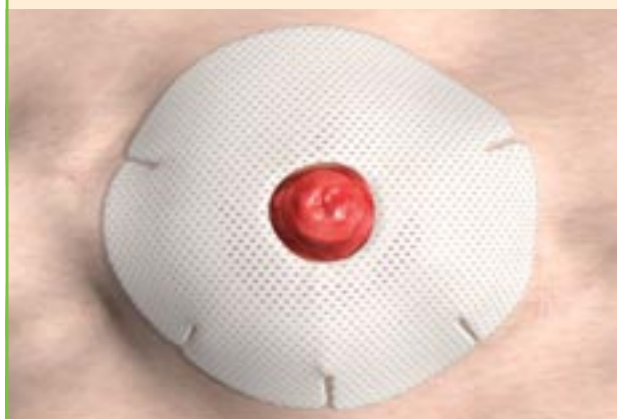


After switching, this colostomist's skin healed within eight weeks and the wafer, containing extracts of Aloe Vera, helped to soothe her sore skin.

Conventional wafers can crease, causing leaks and sore skin.



Confidence® Natural with Flexifit® has five sides that conform to your body's natural contours.



Flexifit® wafer shown without pouch for demonstration purposes

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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.

Frances Townsend writes....

Being able to talk about 'living with a stoma and colostomy' and listening to other people talk about their experiences has been a real revelation to me.



Frances writes... So I was going in to hospital to have a piece of my colon removed and then reconnected – no problem.

After my op – as I came round everything took on a dreamlike quality I was 'somewhere' connected to tubes, pipes, etc., my body no longer mine was completely taken over. Slowly I realised I had a colostomy bag on my tummy and felt overwhelmed by the reality – I really didn't think it would happen to me.

My surgeon visited me and was so apologetic that I had been given 'a bag'. He said there had been no alternative that there was nothing more he could have done and that I couldn't be reversed – quite a shock

to the system. After a few days as I recovered from my operation I felt so very depressed about it all, then to make matters worse I had what can only be described as an explosion! A great big mass of I don't know what (but I did of course) poo all over me! I went into a fit hysterics, big time.

The ward nurses called the stoma care nurses and they arrived in force. I said, 'No way was I going to look at it or my stoma' they agreed and said I didn't have to this time. They cleaned me up with such kindness and understanding but said – I would have to look at it tomorrow.

That evening I had another visit from my surgeon. 'I understand you had a bit of an explosion this afternoon', he said kindly. 'Yes!' I said, 'I'm laughing now but I wasn't laughing earlier'. He smiled, 'No, I know, I completely understand'. I have never forgotten those few words they meant so much to me.

That was well over a year ago now. When I came home I got on with it as you do but I wasn't very happy. My husband Jim tried to help as much as he could, he gave me full access to the bathroom for as long as I wanted bless him! I would always ask him – 'How do I look' – when we were about to go out – but what I really meant was, can you see the bag? He always answered the same, 'No, you look fine to me'.

I did try to come to terms with it all – and when I felt able to – I read about products and accessories – I read their descriptions and tried to understand

some of the terminology, it didn't always register with me! It was all a big learning curve! What was a wafer for goodness sake and what did it do! I didn't stray far from home either. I'd had a few leaks and mishaps and all in all I was not a happy bunny.

One day I received a letter from the Colostomy Association inviting me to a support group meeting I thought about it – the stoma care nurse had mentioned it to me – but I already had a preconceived idea of what it was going to be like. No way was I going to listen to a lot of old people (I'm 71 by the way) talking about their bags in some dingy hall making me even more depressed than I already was. I knew all about the 'bag' and some of the problems and I certainly didn't want it aired in public thank you very much!

After a while when I'd had time to think more about the idea of going to a support group. I plucked up courage and mentioned it to Jim. He said, 'Well, why don't we give it a try'. I can honestly say that since that day I have never looked back. We go every week and I feel like alive!

I have to say when you receive a colostomy you think you are the only person on the planet with one. However when you get used to your colostomy and have had time to think about things objectively you begin to realise – that's a silly thing to think – but totally understandable especially in the early days.

I just wish I'd known more about my mother (who is no longer with us –

sadly) and her medical problems, details of which are scarce, as it may have prepared me for what seems to have been inevitable.

Mum was a very private person when it came to her health but I do know she had a colostomy in her early 80's. From what I understand her bowel had rubbed against the cervix and was leaking. Nobody knew about it so she must have really suffered and in silence. She never mentioned it (the bag that is). One day I was there when a nurse came to see her they both disappeared upstairs and that was that. When I asked what the nurse was there for mum just said, 'It's just a check up'. She didn't want to talk about it and I didn't know what else to say so nothing was said. How sad is that – nil communication. I am not blaming mum but I feel so much for her having now had a colostomy myself.

My son too had a colostomy. A perfectly healthy and very fit man in his mid 30's had stomach ache one evening and when asked, 'What's the matter?' he said, 'Nothing, it's something I ate, it'll go'. Well, it didn't go and he ended up in hospital I can remember seeing him with a distended stomach (like a pregnant woman) waiting to go into theatre. He was there all day. The bowel had burst into his abdomen. Then he was out and into Intensive Care. He didn't stay there long and the medical team were amazed at his recovery they even asked him to join their team as an example to support others.

Both my mum and my son had successful reversals.

The support group I attend has been a real eye opener to me. Being able to openly talk about 'living with a stoma and colostomy' has been really helpful. But perhaps more importantly being able to just sit and listen to others share their experiences about how they live with their stoma – has been a real revelation to me. I'm so glad I plucked up the courage to go and without that courage and the encouragement of the group I might never have written my story.

My fundraising daughter...Carol!



Frances writes...I'm so proud of my daughter Carol (pictured above left), she likes her food and isn't averse to a drink now again but she balances this with going to the gym and keeping fit – she likes to be slim. As part of her fitness regime, Carol enjoys running.

Some time back Carol had the opportunity to enter a sponsored run where she lives. She entered, but who was going to sponsor her? Yes, her Mum of course and who was she going to run for – the Colostomy Association!

Carol donned her Colostomy Association Poloshirt and ran 10k for the first time in her life! I captured her last minute spurt on camera! Here she is with her medal glinting in the sunshine! A real achievement – and a delighted Mum!

At the last count the money raised for CA came to £600.00 – I would like to thank Carol for running and everyone who sponsored her!



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 updated both in **Tidings** and **online visit: www.colostomyassociation.org.uk**. If you know of a **support group** not mentioned in our listings please get in touch...**e-mail: cass@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

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:

Bishop Auckland Stoma
Care Group
Contact: Betty 01388 814535
Jen 01325 311266 or
Maureen 01388 818267

Cumbria:

Grange Cancer Support Group
Contact: Marie 015395 33279

Derbyshire:

Stockport Support Group
Contact: Angela Simpson
0161 419 5059

Lancashire:

Oldham Stoma Support
Contact: June Wilde 0161
312 5538
Tameside Ostomisticles
Contact: Paul Seavers 0777 1359046
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:

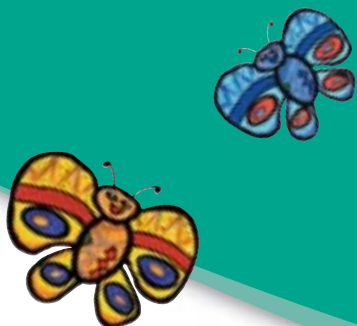
Northumberland Cancer Support
Contact: Mary Miller 01434 622 392
Jim & Dee - 01434 230 398

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



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SUPPORT GROUPS IN YOUR REGION

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: Mrs Joanne Dixon 01908 318262 or 07502 226702

Nottinghamshire:

Nottingham Colostomy, Ileostomy & Urostomy Support Group
Contact: Rosemary Brierley 0115 982 6691
Nottingham Stoma Support
Contact: Mrs B Heath 0115 966 3073
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
Moiria Hammond 01782 627551

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: Alan Wright 01354 653290/07836 661102

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 Bill Hatch (Chairman) 01255 503688
Brian Waller (Secretary) 01206 540449
Optimistic Ostomates
Contact: Angela Taylor/Carol Booth 01702 385509 or 01702 385510
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: Anastasia 01727 760 981
Hertford Stoma Support Group
Contact: Ralda 01992 535311
Stevenage Ostomistics
Contact: Alfred Levy 01767 316958

Lincolnshire:

Friends East Coast Support Group
Contact: Betty 01205 724120/Sheila 01205 364493
Grantham Support Group
Contact: Bobbie/Amanda: 01476 464822
Email: grantham.colorectal@ulh.nhs
March Group
Contact: Maureen 01754 874 485
Sutton Bridge and Long Sutton Ostomy Group
Contact: 01406 351617

Norfolk:

Kings Lynn Ostomy Friendship Support Group
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 & District Stoma Group
Contact: Jessica Pitt 01638 515525

England - South East

Berkshire:

EBOC (East Berkshire Ostomy Club - Bracknell)
Contact: Jackie Dudley 01344 426652
WBOC (West Berkshire Ostomy Club - Reading)
Contact: Jackie Dudley 01344 426652

Hampshire:

COGS (Colostomy Only Support Group)
Contact: Sarah Anderson 07907 820125
Solent Ostomates Support Group
Contact: Carole Summer 07527 707069
Solent Ostomates Support Group (New Forest Branch)
Contact: Carole Summer 07527 707069
Wessex Urology Support Group
Contact: David Morris 02392 361048

Isle of Wight:

Optimistics
Contact: Stoma Nurse Natalie Sayer SCN 01983 534009
Semi Colon Group Isle of Wight
Contact: Tony Crowson Chairman 01983 559326

Kent:

Ashford Stoma Support Group
Contact: Ron Huckstep 07941 310681
Margaret Webb 01233 628807
Atoms Support Group
Contact: Maria Culleton SCN 01227 769679 or 07827997424

Dover & District Stoma Support
Contact: Maria 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:

Homerton Hospital Bowel & Stoma
Support Group
Contact: Toni Johnson 0208 510 7599
Angela Davy 0208 510 5318
Shepherd Bush Stoma Support Group
Contact: Roslyn 0208 354 0121
or Jackie 0208 740 4790
South Woodford Support Group
Contact: Christina 0208 5356563
Surrey & South London Bowel Cancer
Support Group
Contact: Sue Berry: 01737 553134 or
John Amos: 0208 668 0796

Middlesex:

Inside Out
Contact: Bob (Chairman) 0208
4284242 Sarah Varma 0208 2354110
Semi-Colon Club
Contact: Pat Black/Katheryn Foskett
01895 279391

Oxfordshire:

Oxfordshire Ostomy Fellowship
Contact: Pat Longworth
01235 524163

Surrey:

Epsom & District Stoma Support
Group
Contact: Sheena 01372 735925

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:

Hayle's Angels Stoma Support Group
Contact: Sue Hatton
01326 340058
Ostomist and Carers Support Group
Contact: Christine Davey
01208 831471
Optimists
Contact: Sue Hatton 01326 340058

Devon:

Mid Devon Ostomy Group
Contact: Janice Parkyn
01363 776417
Devon IA
Contact: Margaret Bond
01392 447374
Devon Stoma Support Group
Contact: Donna Ashbrook
01626 854862

Dorset:

Colostomy, Urostomy, Pouch &
Ileostomy of Dorset-CUPID (West
Dorset)
Contact: Beryl Andrews
01202 483303

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: Anita Brankley (Secretary)
01656 645602 or
Pat Jones 01656 786103
Royal Glamorgan Stoma Care
Support Group
Contact: Domenica Lear
01443 443053
Swansea Ostomy Self Help Group
Contact: Glynis Jenkins 01792 418245



Northern Ireland

Antrim Area Stoma
Support Group
Contact: Chris Wright
07720 717771

Belfast Royal Victoria
Contact: Sarah Haughey/
Audrey Steele 02890 240503
Ext 3483
Causeway Patient
Support Group
Contact: Mary Kane 028 70 346264
Colostomy Association
Volunteers Northern Ireland
Contact: Chris Wright
07720 717771
Daisy Hill Hospital Newry
Contact: Bernie Trainor
028 3883500 Ext 2222
Mater Hospital Belfast
Contact: Karen Boyd
028 90741211 Ext 2329
North Down Stoma
Support Group
Contact: Adrian Ewing
07850 741511
Southern Trust
Contact: Mary Jo/Bernie
028 38612721
Ulster Hospital
Contact: Hazel/Martina
028 90 550498

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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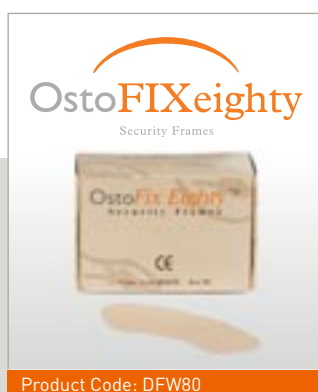


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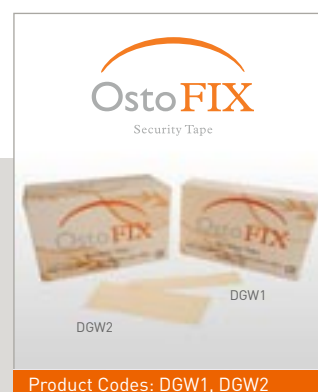
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