

SUMMER 2012 | Issue 26

colostomy  association

# Tidings

Dedicated to Colostomates their Families and their Carers

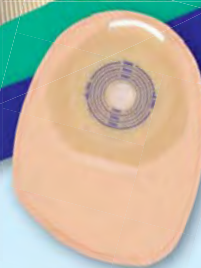


**Cover story**  
**Pathways to a colostomy**  
**Paul's story...**

**Feature**  
**Focus on**  
**Cancer Treatment**

Our warmest congratulations to HM The Queen on the occasion  
of her Diamond Jubilee 1952 – 2012

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# welcome to SUMMER



## Welcome to the summer issue of Tidings...

What a year 2012 is turning out to be...the Queen's Diamond Jubilee celebrations last month...just days until the opening ceremony of the London Olympics...Euro 2012 and now Wimbledon...phew, what's next!

Events like these are truly inspirational! What an incredible effect they have on individuals, communities around the UK and across the globe! The recent weather has been somewhat unpredictable but has not managed to dampen people's spirits!

Watching the Jubilee festivities on television with my family and friends was wonderful – just think how many people were brought together by that special weekend! The crowds around the country at street parties and private gatherings and in London especially along 'The Mall' were amazing, so many happy smiling faces! As television cameras panned around the crowds then cut to a presenter who asked people if they were enjoying the celebrations – I wondered as they chatted if any were colostomates!

That's it I thought...how do you know? Having a stoma and colostomy is not obvious to other people! You can be in the middle of a crowd and be totally unaware that anyone around you is 'living with a stoma and colostomy' but they are!

I am one of those people that other people talk to, I don't know why but if I'm standing on a platform at a railway station or waiting in a queue – people start talking to me! It always amazes me when the conversation turns to that inevitable question...'What is it you do again?' I am delighted to say, 'I work for the Colostomy Association as Tidings Magazine Editor, PR and Communications Manager'. Their reply...'Oh! That must be really interesting...my cousin has a colostomy...or one of my best friends has just had a colostomy,' and that's it they're off – there's no holding them back – it's great! The really lovely part is that they are always so supportive of their family member or friend – some say they have never heard of the Colostomy Association and I say well you have now and signpost them to the office, the CA Facebook group and the website!

So, by talking out loud about – 'living with a stoma and colostomy' – we can help find people who may otherwise remain hidden in the crowd unaware of the support and reassurance available to them from the Colostomy Association.

As someone said to me recently, having a stoma is considered a 'hidden disability' – unlike other disabilities it is – out of sight, out of mind. For colostomates the word 'disability' is not quite right because for people who have a stoma and colostomy who have been seriously ill – their 'stoma and colostomy' gives them the 'ability' to 'live' and to continue with the rest of their lives! It really is up to the individual to choose if they want to speak out about having a stoma and colostomy – as for some it is a very private affair.

Voicing our views and opinions may become more of a necessity in future as changes introduced in the Health and Social Care Act may impact on the NHS and in turn on patients. Recently, the Colostomy Association

has become aware of an increase in the level of calls and emails around fulfilment of prescriptions – particularly relating to GPs, surgery staff/managers and pharmacists. To help the Association understand more about this activity we would appreciate your help! Please fill in and post the form on Page 18 and list any experiences or problems you have 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., please continue on a separate sheet if necessary. Duncan Wells – CA Trustee has written an article, which appears on Page 30, and highlights a patient's recent experience. Duncan asks pertinent questions and makes some interesting observations. Remember the Colostomy Association is your voice so please let us know what is happening around the country. Your feedback is essential and much appreciated.

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

**Email:**  
[editor@colostomyassociation.org.uk](mailto:editor@colostomyassociation.org.uk)

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

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all your regulars

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

## About...the Colostomy Association

The Association represents the interests of colostomates and other ostomates. We provide support, reassurance and practical information to anyone who has or is about to have a Colostomy.

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

Simply contact us by post:

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

By telephone:

**General Enquiries:** 0118 939 1537

Stoma care queries only:

**Freephone Helpline:** 0800 328 4257

By E-mail:

[cass@colostomyassociation.org.uk](mailto:cass@colostomyassociation.org.uk)

Find us on Facebook:



Simply visit our **website**

and **register** at:

[www.colostomyassociation.org.uk](http://www.colostomyassociation.org.uk)

## Don't delay... Donate Online today!

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



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



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	2012
Summer	July	2012
Autumn	October	2012
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## EDITORIAL TEAM

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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.

### Disclaimer:

The display, description or demonstration of products and services or the inclusion of advertisements, inserts and samples within Tidings Magazine does not constitute an endorsement or recommendation of these products and services by the Colostomy Association.



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## In touch – update from the CA office...

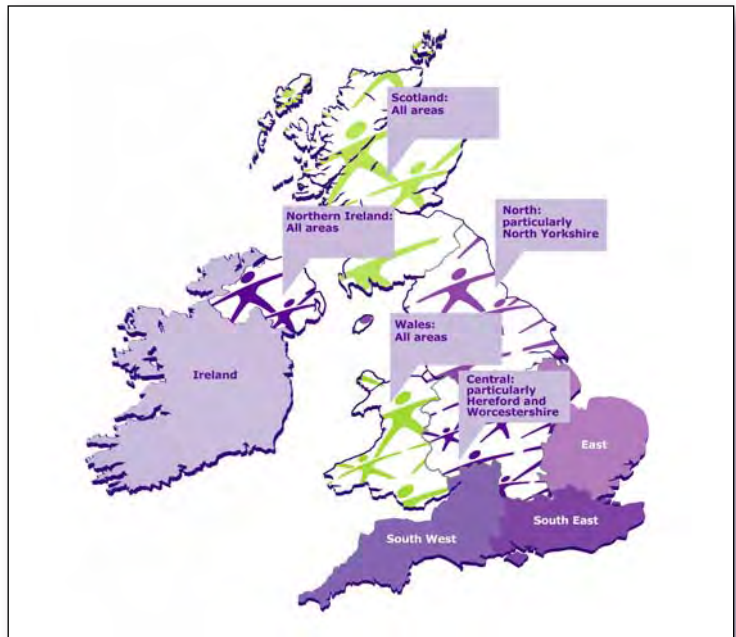
**Dear Readers...**daily activities continue a pace as the CA office continues its pivotal role – providing information, support and reassurance to colostomates, family members and carers. We are pleased to report that healthcare professionals and in particular stoma care nurses are repeatedly requesting our patient support literature and contact remains high. We especially recognise the major importance of 'signposting' people to the appropriate healthcare professional and continue to do so. Our volunteers are increasingly in demand – in the CA office and around the UK – CA is focussing on expanding its volunteer base – training being a high priority. The Colostomy Association continues to reach out via its staff, volunteers, support services, Tidings magazine, website and through the CA Facebook group...to make a difference to the 'real life' experiences of those 'living with a colostomy'.

**CA Open Day...**we have decided not to hold an open day this year but to use the allocated resources to concentrate on our volunteer programme which has really taken off. We have been able to hold various seminars and workshops to train up potential volunteers and now have a much larger pool of volunteers to call on for tasks. If you'd like to learn more about the scheduled manufacturers' open days on offer across the UK, these are published on our website.

### Call to action...MORE support needed...around the UK! Can YOU imagine yourself as a CA volunteer!

**CA Volunteers...**we have a wonderful team of more than 90 valued volunteers who are involved in a variety of tasks such as representing the CA at manufacturers' open days, visiting patients pre and post op and answering our 24 hour helpline.

However, we urgently need more helpers in Scotland, Wales, Herefordshire, Worcestershire and North Yorkshire. If you live in the regions where we have a shortage (see map opposite) and would like to get involved, please get in touch... email: [cass@colostomyassociation.org.uk](mailto:cass@colostomyassociation.org.uk) or apply online via the CA website: [www.colostomyassociation.org.uk](http://www.colostomyassociation.org.uk) or call the admin team for an application form. Please be assured your help will be much appreciated!



#### Photo ID Card...

following the publicity of the new photo ID card pictured in the spring edition of Tidings, the office was inundated with requests. We are a man down at present and hope to appoint a replacement administrator in the coming weeks which will greatly help with our ongoing high workload so please bear with us.

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)

#### National Key Scheme - Key and photo ID card purchase

Title: \_\_\_\_\_  
 Name: \_\_\_\_\_  
 Address: \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_ Postcode: \_\_\_\_\_  
 Tel: \_\_\_\_\_  
 Email: \_\_\_\_\_

**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: / /2012

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



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Nicholas, an ostomate since 2010

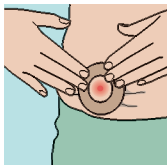


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Brava Mouldable Ring is part of the new range of accessories from Coloplast, designed to reduce leakage and take care of your skin.



### How to use

Place the Brava Mouldable Ring over your stoma and mould it to create a durable and tighter seal between skin and stoma. Lastly, mount your appliance's baseplate on the ring for a better fit.

[See full instructions for guide of how to use](#)



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# Pathways to a Colostomy...

**Prostate cancer is the most common cancer in men in the UK. Over 40,000 men are diagnosed with prostate cancer every year. 250,000 men are currently living with the disease...in 2000 Paul Reynolds was diagnosed with prostate cancer...discussions with his consultant revealed no cure...only permanent hormone treatment aimed at controlling the cancer...so opting for surgery...Paul was marked up pre surgery for both a colostomy and a urostomy (expecting only a urostomy)...with an outside chance of both...**



Paul pictured with his wife Jan

**Three years ago Paul Reynolds came by his colostomy by what seems to have been one of the less usual routes...this is his story...**



I came by my colostomy almost three years ago, by what seems to have been one of the less usual routes – while my prostate was being removed. By comparison with many previous contributors to Tidings, my path has been much less traumatic, thank goodness.

I developed prostate cancer in 2000. The diagnosis started with typical minor urinary problems, with blood tests showing a moderately high PSA level of around 12 (PSA is a test for high levels of prostate activity, which may or may not be due to cancer; the 'normal' level is around 4). The scans and biopsies that followed indicated that there was cancer, and that it had probably already spread outside the prostate gland itself, so rather than remove it surgically, we decided to treat it with a course of radiotherapy. Five minutes every day for 7 weeks, onto the table under 'The Machine' for a completely painless treatment, one's trousers having been removed for the radiation by some quite delightful young nurses (always look on the bright side!). That should have done it - burned it out.

At that time, a particularly compelling study had been reported in the New England Journal of Medicine – funny how one's reading matter changes! Hormone treatment for some years after radiation had been found to increase life expectancy, so my radiation was followed by three years of hormone treatment – a small capsule injected below the skin of the stomach every 12 weeks. I hated hormone treatment; it depresses the production of testosterone, but produces swellings where a man shouldn't have them, and frequent hot flushes. For the first time, I understood and now have great sympathy with women of a certain age. But it worked

– no further treatment and for some years the continuing regular PSA checks showed a minimal level.

By 2007, however, the PSA level was going up again, and something needed to be done. By this time a new treatment had been introduced – cryotherapy (that just means 'freeze it out'). Tubes were pushed up from underneath into the prostate gland and freezing argon gas passed through, killing the cells, including, we hoped, all the cancer cells. A couple of days in hospital, a 'supra-pubic' catheter fitted for a few weeks (put through your stomach directly into your bladder – when it was removed I was blowing from the hole in my stomach like a whale!), and a couple of months later my PSA was back down. Six months later I could ride my bike again - carefully.

My PSA stayed down until 2009, when again it went inexorably up and up (be patient, this is where the colostomy comes in). The options were permanent hormone treatment, aimed at control but not offering any hope of cure, or, my Consultant mentioned almost in passing, surgery to remove it after all.... but that would probably require a stoma and badly affect my quality of life, he said, having a bag for the rest of time; he was really off-putting about that. I thought about it, a lot; I'm even now only 67. Anyway, my wife Jan and I decided to go for broke and ask for the op, but even then I had to persuade my man that he should carry it out – 'I'm not old, I'm reasonably fit; if you won't carry out that operation on me, who are you going to do it on?' It was eventually agreed, but I was warned it would take some time to arrange – he wanted three consultants together for the operation, the greyest-haired ones in the



hospital, he said (Royal Berks, Reading). He specialised in prostate removal, another in stomas, and (I was asleep for 6½ hours) – I think the third was the anaesthetist.

Nearly three months later, I woke in hospital and found myself minus my prostate but having acquired a colostomy. Before the op I had been marked up for both a colostomy and a urostomy, had been expecting a urostomy but had accepted the outside chance of both. The colostomy was because part of my rectum had to be removed with the prostate gland; investigation during the operation showed that the previous treatments had in effect welded them together. My bladder, though, had been retained, so no urostomy. Now we had tried all three approaches to eradicating my cancer – burn it out, freeze it out, and finally cut it out. I was amused later to see the operation classified as a ‘salvage prostatectomy’ – as if I were some poor soul rescued by the Salvation Army. I spent 6 days in hospital, fought to get out, and started to recover properly when I reached home - my first real sandwich put new life into me.

I had a catheter again, fitted normally this time, and in a few weeks was able to hobble about the lanes, regaining strength. The catheter came out after 4 weeks, but unfortunately so did the urine – it wouldn’t stop! I used huge quantities of pads, soggy pads – horrible. This time I sympathised with my young grandchildren and their nappies! Then

our District Nurse, bless her, came up with penile sheaths – you just roll them on and connect the end via a tube to a leg bag, with no need for bladder control at all. Freedom! I recall so clearly telling Jan that if it got no better than this, I could live with it. I rejoined normal life, drove around the country (it was actually quite convenient when you needed a pee, with the leg bag full – just stop in a country lay-by, roll the trouser leg up to the knee...), went to business meetings, church, walked the lanes ... great.

Haven’t said much about my colostomy, have I? (though I must say that I saw Jan scratching an insect bite on her stomach the other day – said to her ‘Stop that straight away! I scratched and scratched at a spot like that but it went right through, and now I have to have a little bag on it all the time!’) Really, the colostomy was just no problem, certainly compared with my urinary function. Even now, when I have regained complete urinary control, my colostomy causes little concern. I used to get itching of the skin around the outside edge of the bag, but now use barrier cream rather than skin-forming protection, which has solved that. I have never had leakage outside the adhesive wafer – only once (recently) had an ‘accident’, when a half full bag split, fortunately at home. I usually change the bag each morning and night, remove it before bathing in the evening for a good splash around, replacing it before I go to bed; I occasionally put on a fresh bag before

an evening meeting, for peace of mind. I’ve considered irrigation – maybe, when I have time. I do everything I could do before – including growing most of our vegetables, keeping chickens, turkeys and fattening pigs – and butchering them too. I’ve reprimanded my consultant for his negative attitude to a stoma – all in all, my quality of life has improved. I certainly appreciate it more; reading in Tidings about the way others with far worse problems have carried on with life inspires you. Seeing the youngsters from Breakaway at the Open Day a year or two ago at the Heritage Motor Museum, Gaydon was heartening, to say the least, and I’ve experienced so much care and support from our health care professionals at all levels, too.

When friends say ‘you do look well’ in a surprised tone, I just point out that it is precisely because I have a colostomy that I do feel well! It’s just plumbing, that’s all.

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### Editors Comment

To learn more about **Prostate Cancer** visit: [www.prostatecanceruk.org](http://www.prostatecanceruk.org)



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

**Donations**  
When sending your donation/s please mark your letter/cheque with Tidings Issue 26.... Thank you!

**Dear CA,**

My wife Patricia and I recently celebrated our Golden Wedding Anniversary. On our invitations we requested that instead of giving presents our guests if they wished could make a donation to be shared between our two chosen charities. Many guests did donate and we received a whopping £440,00. As a fellow colostomate of some thirty-four years we chose the Colostomy Association as one of the chosen charities. We are delighted to be able to send a donation of £220.00 we know it will be put to good use. Thank you for all your help and guidance over the years keep up the excellent work!

**Thank you everyone for your kind donations**

people's lives. The funds raised will go to the Colostomy Association – to support its work. Please visit: [www.justgiving.com/LJ-Ainger](http://www.justgiving.com/LJ-Ainger)

**L.J.A**

I also did a charity skydive on Sunday 11th of March in memory of my wonderful, brave Uncle who after losing his fight with bowel cancer sadly passed away last year. My Uncle did a lot of work for the Colostomy Association – a relatively unknown charity that makes such a difference to people's lives! Every donation counts however small or large everything is appreciated! So please make a donation however much, it's going to a great cause! Please visit: [www.justgiving.com/Becky-Ainger](http://www.justgiving.com/Becky-Ainger)

**B.A**

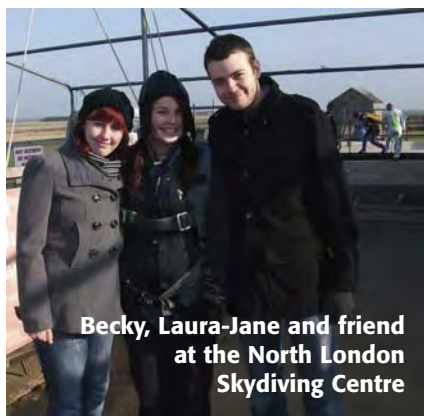
If you would like to donate to this cause in Bob's memory, please send a cheque to the CA – with a note marked for the Fund or visit: [www.justgiving.com/kevin-buckley78](http://www.justgiving.com/kevin-buckley78)

**Research can make a difference!**

## 500 Club... March 2012 Draw Winners!

Mrs J Dudley	£ 364.00
Mr P Foulger	£ 182.00
Anonymous	£ 72.80
Mr A J Thomas	£ 72.80
Mr C L Wilson	£ 72.80
Mrs R H Sneeton	£ 36.40
Ms A Robinson	£ 36.40
Mrs S M Mayston	£ 36.40
Anonymous	£ 18.20
Mr B Herpe	£ 18.20
Mrs G Marsden	£ 18.20

**Yours sincerely,  
P.R**



**Becky, Laura-Jane and friend at the North London Skydiving Centre**



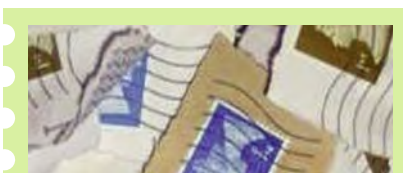
**Monies raised to date for the Colostomy Association by both girls amount to £548.50...thank you!**

### Skydiving event in memory of Bob Buckley...Colostomy Association Volunteer...

I did a charity skydive on Saturday 10th March 2012 in memory of my Great Uncle Bob. He was a volunteer with the Colostomy Association who helped make a big difference to

### BOB BUCKLEY RESEARCH FUND

The Fund was set up in January 2012 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 your donations as the monies will be designated to specific research projects.



**Used Stamps...**we received an excellent response to our request for used stamps – thank you all so much for sending them in as it will help us raise vital funds!

However, please ensure that each stamp needs to have a 1cm border to make them of value to the Colostomy Association. Please continue to encourage your friends and family, at home and abroad, to save their stamps for the CA!

**Contact CA head office for further information on 0118 939 1537.**

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



## Because we're all different

New FreeStyle Vie® Convex is ideal for you if your stoma is recessed. Its advanced, flexible flange means you can feel secure with a leak-free fit. Combined with the comfort of a skin-friendly pouch, belt loops for added protection and a split back for easier monitoring, FreeStyle Vie® Convex is designed with your individuality in mind – helping you regain the freedom to do the things you love.



**FreeStyle Vie®**  
**CONVEX**

Manufactured by **Welland** a CliniMed® Group company

For a free sample of FreeStyle Vie Convex please complete the coupon and return it to: **CliniMed Ltd., FREEPOST HY241, High Wycombe, Bucks. HP10 8BR** (NO STAMP REQUIRED)

Mr/Mrs/Ms: \_\_\_\_\_ Initials: \_\_\_\_\_ Surname: \_\_\_\_\_ Address: \_\_\_\_\_

Postcode: \_\_\_\_\_

Tel. No.: \_\_\_\_\_ Email: \_\_\_\_\_

I understand that this request will be handled by CliniMed Limited or SecuriCare (Medical) Limited. I would like my details to be kept on file, so that I can be kept up to date with information about relevant new products and services.

Manufactured by Welland® a CliniMed® Group company. Welland products are distributed in the UK by CliniMed Ltd. Tel: 01628 850100 Fax: 01628 527312 Email: enquiries@clinimed.co.uk or visit www.clinimed.co.uk. For N. Ireland contact Fannin (N.I) Ltd. Customer Support Tel: 02890 735588 or email: info@fanninni.com. For Republic of Ireland contact Fannin (ROI) Ltd. Customer Support Tel: 003531 290 7047 or email: info@fannin.ie. CliniMed Ltd, a company registered in England number 01646927. Registered office: Cavell House, Knaves Beech Way, Loudwater, High Wycombe, Bucks HP10 9QY. CliniMed®, Welland® and FreeStyle Vie® are registered trademarks of CliniMed (Holdings) Ltd. ©2012 CliniMed Ltd. 1514/0312/1

# Update on stoma care products and services

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

## Comfizz are supporting juniors...



As well as the current range of underwear and waistbands for juniors we have now produced the girls and boys support vests. This complete range of discrete and stylish support wear allows children to be as children should be...carefree, to play without concern for their stoma...Seamless and breathable for comfort – longer length than standard vests for greater coverage to prevent riding up – keeps everything covered up and securely out of the way – gives discretion when changing for PE at school... comes in fun colours, so attractive for children. Available in August to purchase at [www.comfizz.com](http://www.comfizz.com) or on prescription...For more information call 01757 229 531



## Independence Products Ltd...

are pleased to announce that all of their Stoma Accessories have been updated on the Scottish Drug Tariff as of 1st April 2012, therefore all are available on prescription in Scotland.

This includes:

- ARW1: Independence No Sting Adhesive Remover Wipes (pack of 30 wipes)
- BW1: Independence No Sting Barrier Film Wipes (pack of 30 wipes)
- P200AS: Absorbent Strips (pack of 200 strips)
- PR310: Independence Odour Eliminator Lemon and Lime Pump Spray (59ml)
- RS1: Adhesive Remover Spray (50ml)
- SB2: AcuBond Flange Extender Strips (Pack of 30 strips)
- SB1: SilBond Silicon Glue (30ml)

All of these products can be ordered via your normal supplier.

To try a sample on selected products please contact the friendly staff here at Independence Products Ltd on 0115 9757254 or email us at: [samples@independenceproducts.co.uk](mailto:samples@independenceproducts.co.uk) or visit our website [www.independenceproducts.co.uk](http://www.independenceproducts.co.uk)



- Contains a very pleasant fresh citrus scent
- Available in aerosol and sachet formats
- Available on prescription now!

## NaturCare IPD... In Pouch Deodorant

New and Available on Prescription...We are pleased to announce the latest addition to the Opus Healthcare range of stoma management products, NaturCare IPD (In Pouch Deodorant).

NaturCare IPD will complement the existing NaturCare aerosol products, which will remain available on prescription.

- A highly effective deodorising powder in a simple to use sachet
- Contains a very pleasant fresh scent
- Makes disposing of used pouches a less "odour challenging" experience
- Contributes to peace of mind when pouch is in use

For samples please visit [www.opushealthcare.co.uk](http://www.opushealthcare.co.uk) or call free of charge 0800 4587605

## Lift Plus Citrus Adhesive Remover

New and Available on Prescription...We are pleased to announce the latest addition to the Opus Healthcare range of stoma management products, Lift Plus Citrus Adhesive Remover.

Lift Plus Citrus Adhesive Remover will complement the existing Lift Plus products, which will remain available for those that prefer a non-scented version.

- Effectively removes adhesives and residues, quickly and painlessly

**Handle with care**

Fragile and sensitive skin needs to be treated with care. That's why we've developed Appeel® – a medical adhesive remover clinically proven to remove adhesives gently,<sup>1</sup> even from the most sensitive skin. Appeel leaves skin feeling clean and residue free, ready for the next appliance or dressing application.

Appeel spray can be conveniently sprayed at any angle, allowing easy access to hard to reach areas. Appeel wipes remove adhesive so gently that they can even be used on the face as well as the rest of the body. The Appeel range handles skin with care, meaning no sting and no trauma for even a baby's skin.



**Appeel**  
NO STING

Medical adhesive remover

For a free sample of Appeel®, please complete the coupon and return it to: **CliniMed Ltd., FREEPOST HY241, High Wycombe, Bucks. HP10 8BR** (NO STAMP REQUIRED), call our free confidential Careline **0800 036 0100** or visit **www.clinimed.co.uk**

Mr/Mrs/Ms: \_\_\_\_\_ Initials: \_\_\_\_\_ Surname: \_\_\_\_\_ Address: \_\_\_\_\_

Postcode: \_\_\_\_\_

Tel. No.: \_\_\_\_\_ Email: \_\_\_\_\_

I understand that this request will be handled by CliniMed Limited or SecuriCare (Medical) Limited. I would like my details to be kept on file, so that I can be kept up to date with information about relevant new products and services.

Reference: 1. Stephen-Haynes, J. 2008. Skin integrity and silicone: Appeel® 'no-sting' medical adhesive remover. British Journal of Nursing, 17(12), pp.792-795.

CliniMed® and Appeel® are registered trademarks of CliniMed (Holdings) Ltd., a company registered in England number 01646927. Registered office: Cavell House, Knaves Beech Way, Loudwater, High Wycombe, Bucks. HP10 9QY. ©2011 CliniMed Ltd. 1336/0211

## OakMed...offers you OakMedGold and Website Update!

We are very pleased to offer you - OakMedGold - your home delivery service. Giving you more choice! We deliver all of your stoma products and accessories from any company. We work discreetly behind the scenes to deliver your order nationwide. We offer a luxury toilet bag when you register with the service which can include curved scissors, folding mirror, clothing clip. This is alongside the items you will receive with each delivery (soft wipes, disposal bags etc.) Complimentary Items – these are also available to you with your orders and include a radar key, radar key booklet and mattress protector. **For further information please see our advert on page 49 or phone 0800 592786**

Oakmed has launched a newly updated website with many informative and helpful areas including our Product selection Wizard. This can help guide you through the baffling array of different products available to the correct appliance for your needs. **Take a look at: [www.oakmed.co.uk](http://www.oakmed.co.uk)**



## ConvaTec expands its stoma care accessory range...

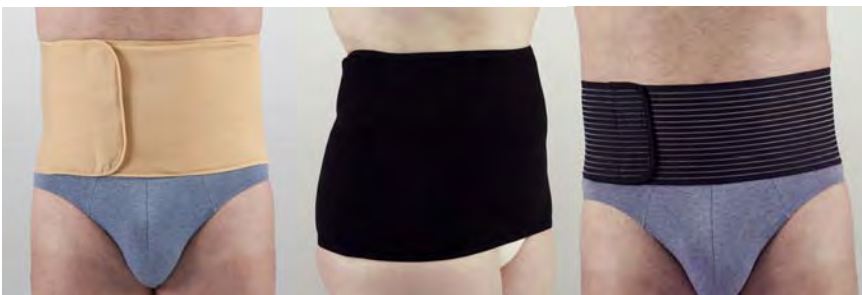
ConvaTec is delighted to announce that it has recently increased its stoma care accessory range, with the purchase of Trio Healthcare International Ltd. Trio Healthcare International Ltd is a UK-based company with an innovative



range of stoma care accessories including Niltac™ sting-free medical adhesive remover ([www.niltac.com](http://www.niltac.com)), Silesse™ sting-free skin barrier ([www.silesse.com](http://www.silesse.com)) and Diamonds™ Gelling Sachets with ActiveOne™ odour control ([www.triodiamonds.com](http://www.triodiamonds.com)).

**For more information on the Trio Healthcare International product range, please call 01494 867221, email [info@niltac.com](mailto:info@niltac.com) or visit the website addresses above.**

## OstoMART are pleased to announce that their HiLine range of support belts are now also available in Black and Beige colours...



The new range of colours are available in our breathable Res6 and Res6b belts, our lightweight Res3 and Res4 belts and our seamless two way stretch Res7 and Res8 belts. All HiLine support garments are available on prescription and are unisex. We provide a FREE hole cutting facility if required and the belts are available in sizes Small, Medium, Large, X-Large, XX-Large and XXX-Large.

HiLine have been making support garments for over 20 years and our garments are designed and manufactured in the UK. Almost all our garments come with a safe, effective and efficient antimicrobial and antibacterial Silver based coating which makes them MRSA and E Coli resistant. This coating also has an "Active Odor Control" benefit that inhibits the growth of odour-causing bacteria.

**To order or for further information please call the HiLine team on 0800 220 300, visit [www.ostomart.co.uk](http://www.ostomart.co.uk) or email [enquiries@ostomart.co.uk](mailto:enquiries@ostomart.co.uk)**

## SASH Medical Ltd...

has recently made improvements to their very popular Leakage and Security Belt. The elasticated belt is now fastened with a clasp that makes it easier to secure around the waist. The flange, which fits between the bag and adhesive section of the pouch, is custom made to suit the ostomists pouch giving greater protection from leakages and added security.



**The 'Security and Leakage Belt' is available on prescription (ref.no. SR103) and is made-to-measure from information given on an Order Form – obtainable from SASH Medical Ltd. Freephone 0800 389 3111.**

## The World Assist Alliance Service from Fittleworth...

Don't get the hump on holiday! If you find yourself delayed abroad, your luggage lost or unfortunately pick up a bug (meaning you require more medical appliances than you packed) - whatever the situation may be, if you find yourself in an emergency without enough medical appliances then simply call Fittleworth and we will deliver your products to you. Fittleworth will arrange delivery from a local supplier within the country you are in; whether you are in a hotel, on a cruise ship, in a tent or a villa!



The World Assist Alliance Service is completely free of charge and part of the Fittleworth service. Prescriptions are not needed, there is no paperwork required and there is nothing to claim back for insurance purposes. You just need to be a Fittleworth customer who has placed a previous order with us. Fittleworth currently work with the following countries; Australia, Austria, Belgium, Bolivia, Denmark, Finland, France, Germany, Greece, Holland, India, Italy, New Zealand, Portugal, South Africa, Spain, Sri Lanka, Switzerland, Turkey, U.S.A and the number is increasing all the time.

**For more information please call our friendly customer service team on 0800 378 846.**



# Work, Rest or Play



## Mariam

Colostomy since 2006  
28yrs old

### Work:

Training to become an  
integrative-relational counsellor

### Leisure:

Charity work and fundraising

**NEW**

## Novalife – gives you control for the whole of your day.

Everyone's life story is different, everyone's story is special. So before we created Novalife, our new generation of pouches, we listened. What we heard gave us the insight we needed to reshape and redefine what we have done before.

Design for Life. [www.dansac.com](http://www.dansac.com)



## FREE Samples

My stoma size is \_\_\_\_\_ mm

My current appliance is \_\_\_\_\_

One Piece  Two Piece

Convex

Ileostomy  Colostomy

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

Fill in the form below or call our dedicated Customer Services Team on **FREephone 0800 581117**

Name \_\_\_\_\_

Address \_\_\_\_\_

Postcode \_\_\_\_\_

Tel \_\_\_\_\_

Email \_\_\_\_\_

REF 1046

**NOVALIFE**

dansac

## 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: \_\_\_\_\_

Tel: \_\_\_\_\_ Email: \_\_\_\_\_

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. The Colostomy Association is a registered UK Charity No. 1113471

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



**NEW** HydroFrame<sup>®</sup> mini

# Security...

## HydroFrame<sup>®</sup> gives you security, comfort and flexibility

HydroFrame hydrocolloid flange extenders provide additional adhesion for your stoma pouch. HydroFrame is cost effective as it can reduce the number of pouch changes by increasing pouch wear time and preventing leaks, especially when putting extra pressure on your flange such as when gardening and playing sport. HydroFrame is the ideal alternative to more aggressive medical tape which can lead to sore skin.

## HydroFrame<sup>®</sup> mini - same security, smaller size

New HydroFrame mini hydrocolloid adhesive strips is the ideal solution where smaller areas of adhesive are required such as paediatrics or areas of sensitive or damaged skin.

For a free sample of HydroFrame<sup>®</sup> or HydroFrame<sup>®</sup> Mini, please call our free confidential careline **0800 036 0100** or visit **www.clinimed.co.uk**.

**CliniMed<sup>®</sup>**

CliniMed<sup>®</sup> and HydroFrame<sup>®</sup> are registered trademarks of CliniMed (Holdings) Ltd. Cavell House, Knaves Beech Way, Loudwater, High Wycombe, Bucks. HP10 9QY. ©2011 CliniMed Ltd.

HydroFrame patent numbers: GB 2 397 230B; EU 1,587,467B1 and 1,736,125B1

1284/0710

**HydroFrame<sup>®</sup>**



Not hearing  
my pouch.  
**That matters.**



Discover more at  
[www.quietwear.co.uk](http://www.quietwear.co.uk)

QuietWear now available on a wider  
range of one and two-piece pouches

#### Hear the difference

- Proven to reduce embarrassing pouch noise found in other ostomy pouches.

#### Feel the difference

- Pouch material feels smooth and is designed to resemble natural fabrics found in most clothing.

#### See the difference

- Now available in Moderma Flex one-piece closed flat (midi and maxi) and one piece closed convex (maxi). Also available in Conform 2 two-piece closed (midi and maxi) pouches.



[www.quietwear.co.uk](http://www.quietwear.co.uk)

To request FREE samples, please contact Hollister  
at **0800 521 377** or email [samples.uk@hollister.com](mailto:samples.uk@hollister.com)

Hollister Ostomy. **Details Matter.**



"Vitala™ has given me a new lease of life"



John Murdoch is not going to let his stoma stop him flying 3,500 miles to celebrate his 60th birthday with his family in Canada.

In 2004, John, from Blackburn, was diagnosed with bowel cancer and had surgery to remove the bottom of his ascending colon, leaving him with a stoma. John had some setbacks over the next year or so, getting a hernia and then breaking his arm badly, all of which meant he was unable to work.

"I got very depressed," John admits, "but was invited to my sister's, in Canada."

"All my family's over there. I've been so many times in the past and travelled from coast to coast – lots of good memories," he says.

Being surrounded by his family, John says, really recharged his batteries. He came home and found a new job, but still had some health issues to face.

In 2009 he was declared free of his cancer and a year later decided to take early retirement.

#### **Looking for control over my bowel**

Over this time John had tried every ostomy bag on the market, but because of the shape of his stoma, he had trouble finding the right product.

"I said to my stoma nurse that I wanted something that would give me control of my bowel," John explains. He found that irrigation was working for him. It gave him some freedom, as he enjoyed going on railway trips but never had the confidence to stay overnight anywhere but home.

At the end of last year, his stoma nurse told him about a new product on the market and that she wanted to recommend him for a trial. His stoma nurse had to be trained on it first and then in February this year John started to use the Vitala™ Contenance Control Device (CCD) from ConvaTec.

"A lot of people have said to me; you're changed! They tell me I look better."



Because of the shape of his stoma, he had been prone to having problems with leaks, so he had tried different sized flanges and bags. John was immediately won over: "the bags were marvellous," he says. "I could go out and knew it would work as it was supposed to." Vitala™ CCD can be worn for up to 12 hours in a 24-hour period and it is important to work up the wear time when you first use it.

"I wore it for 2 hours, then 4 hours and then up to 12 hours," he explains. "I had no problem at all. It never came off. I've gone from strength to strength!"

"Vitala™ has given me a new lease of life," John says triumphantly.

He had been very depressed last year, but with the new confidence that Vitala™ has given him, he says: "I thought, blow this, I'm going out!"

#### **People tell me I look better!**

John now joins a regular social walking club every other week. "Last week we walked 4.5 miles, led by a ranger and then all went for a lovely meal afterwards." He enjoys the company and the exercise.

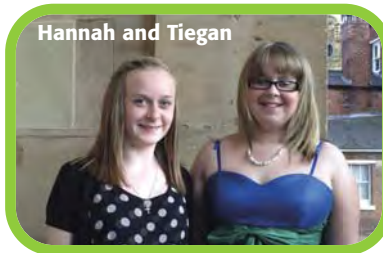
Now he feels better in himself, he has also started some voluntary work. He is also now keen to share his experiences of living with a stoma and has attended coffee mornings for stoma patients and their nurses. Vitala™ isn't right for everyone, as everyone's surgery is different, but John is keen to talk about his experiences.

"I used to be an introvert," John says, "Vitala™ has made a difference."

"A lot of people have said to me; you've changed! They tell me I look better."

He is now looking forward to his holiday in Canada. The long-wear time of Vitala™ means that John has no qualms about wearing the device on the flight. "I'm feeling very positive about this trip!"

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



**A letter from Julie....**

**Dear Tidings Readers'...**

Breakaway is a registered charity supporting children with bowel and bladder dysfunctions and their families.

Every day in the UK a baby is born with, or a child develops a bowel and/or bladder dysfunction. There are over twenty types of conditions, which may cause these problems. Their complexity and frequency range from 1:500-1:145,000 live births.

Bowels and bladders are not openly discussed in public, so some children grow up having to keep their condition a secret. Breakaway, like the Colostomy Association works hard to change public perceptions. Children often have to deal with their problems behind closed doors, feeling totally isolated from their peers.

By society they are not deemed to be brave or courageous. At Breakaway to believe differently.

By providing Breakaway activity weekends and developing family support networks throughout the UK, we offer the opportunity for the children and their families to realise that they are not alone. Our aim is to raise public awareness and to ensure that they receive the support they deserve so that they can grow in confidence and reach their full potential in life.

We rely on the generosity of people and companies to continue our work. All money donated goes to fund families who otherwise would not be able to attend. Having a child in and out of hospital can be extremely worrying, as well as financially and emotionally stressful on all the family.

The following donations would pay for;

- One child to attend a Breakaway weekend = £165
- Family of four to attend a Breakaway weekend = £600
- 10 children to attend a Breakaway weekend = £1,650
- Breakaway weekend = £11,000

Our website gives further information and photographs of our events. A brief perusal of the site demonstrates the effect these weekends have on the children. With this in mind I am writing to ask that you might consider Breakaway for Your Support Group's Charity of the Year 2012 or for a one off donation or to organise a fund raising event.

Please help our amazing children with bowel and/or bladder dysfunctions so that they do not have to face life's difficult journey alone. If you require any additional information or clarification please do not hesitate to contact us.

Yours sincerely,

**Julie Bastin**  
Founder and Trustee



**The Breakaway Ball...** Recently a family who benefited from Breakaway – Max was born with Hirschsprungs disease – decided to organise a ball to raise funds for Breakaway. Mum, Bev Stacey dedicated months of her time to making sure the event was a huge success! **Bev writes...**Max was born in

April 2009 at 32 weeks after a difficult pregnancy; early thoughts were that he had kidney problems, which required medication. After many tests it was clear he had problems with his bowels. Max spent time in four different hospitals and was finally diagnosed at four weeks as having Hirschsprungs disease. Now nearly three years old, Max is funny, naughty, bright but most important happy. (You will be able to read Max's story in the Autumn issue of Tidings). Max goes to a mainstream nursery in Hereford and enjoys all the activities just like any other toddler. All in all it's been a very difficult few years but we have been lucky enough as a family to meet some inspiring people at Breakaway. After attending Breakaway we suggested a ball to help raise funds for Breakaway. In May around 220 attended the Ball at the Shire Hall in Hereford. We were delighted that the Colostomy Association's Facebook group administrators could attend – Sarah Squire, Helen McTurk and Duncan Wells (pictured below) along with other CA members. The total amount raised on the night was £3700, which equates to Breakaway being able to fund approx.22 children to attend one of the Breakaway Activity weekends. To date funds raised amount to £5600 with more funds coming through.



Sarah, Duncan and Helen

**More information about Breakaway...**

**Write to us or send a donation to:**

Breakaway  
PO BOX 7982  
Swadlincote  
DE11 1FB

**Telephone:**  
07903220040

**Email:**  
info@breakaway-visits.co.uk

**Web:**  
www.breakaway-visits.co.uk

**Donate online via:**



<http://www.justgiving.com/breakawayvisits>



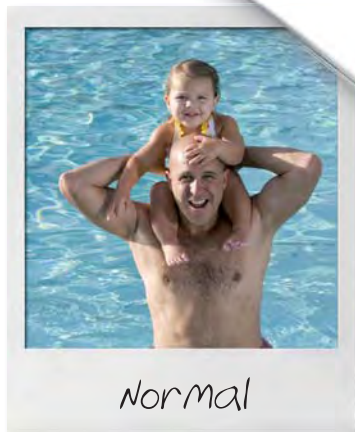
ConvaTec



*Excitement*



*Liberation*



*Normal*

# WHAT'S YOUR WORD?



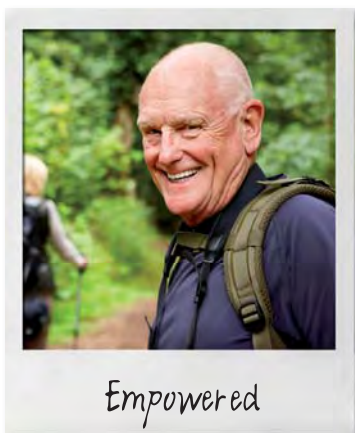
*Control*



*FREEDOM*



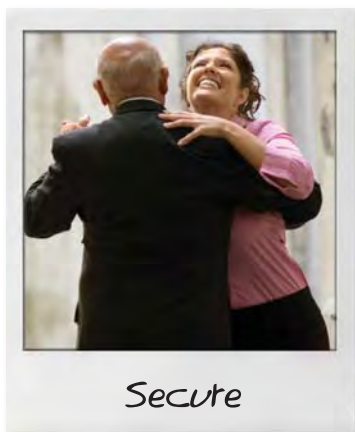
*Exhilaration*



*Empowered*



*Comfortable*



*Secure*



*Confidence*

**Don't just take our word for it. Vitala™ Continance Control Device (CCD) is already changing lives for the better**

The single-use, disposable device provides faecal continence using non-invasive, pouchless technology. Vitala™ CCD is helping to make everyday life for people living with an end colostomy more manageable. To see if Vitala™ can support you call us on 0800 467866, email [vitala.webcare@convatec.com](mailto:vitala.webcare@convatec.com) or visit [www.vitala.com](http://www.vitala.com)



Follow us on Facebook and Twitter

[facebook/ConvaTecStomaCareUK](https://www.facebook.com/ConvaTecStomaCareUK)

[@ConvaTecUKI\\_Ost](https://twitter.com/ConvaTecUKI_Ost)

Not all images represent actual product users. © iStockphoto



VIT7

# Irrigation and you...

**Sue Hatton Executive Trustee and passionate colostomy irrigator writes...one of the most rewarding things 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...**The following are just a few examples from my postbag...

A great hand written letter came in from Mr. P.G...

Dear Sue,

You may remember me, I wrote to you in 2010 thanking you for talking about Irrigation in Tidings. Yes...it's over two years (05-05-10) since I started 'Life Changing' Irrigation! Please keep up the good work telling everyone about Irrigation as you did in the Spring Issue 2012. If you wish to pass on my telephone number – please do!

Regards,  
Mr. P.G

Mr. P.G sent in a donation to the Colostomy Association and wishes it were more but says he is on a state pension. We do have his number if anyone would like to chat to him, so please contact the office. Thank you Mr. P.G you are a star!

Eleanor from Northern Ireland also got in touch...and told me that she wanted to irrigate, but that the nurses in Ulster Hospital were unsure of the technique. So, they contacted the stoma care nurse at the Royal Hospital in Belfast, who then taught Eleanor the skills she needed!

**Sue comments...**Fantastic that the nurses are openly saying that if they don't know how to do it, they will find someone who can!

Tips come from CA volunteer and irrigator...Sue Hanham – who recommends the Asda sterilising kit,

which is much cheaper than the brand we associate with baby bottles! This CA volunteer always travels with her butcher's hook (which has had the sharp ends filed down). A handy addition to her colostomy irrigation kit – as it has enabled Sue to hang up her water reservoir wherever she goes. Sue needs to have a cup of coffee and something to eat before she begins to irrigate. She also uses a thermometer to test the water temperature, as her colon doesn't respond well if the water is not at just the right temperature. I have to admit that I just stick my hand into the water and if it's OK off I go! CA Volunteer – Sue has been asked by her stoma care nurses to speak to other patients. Her GP has also put her in touch with new colostomates.

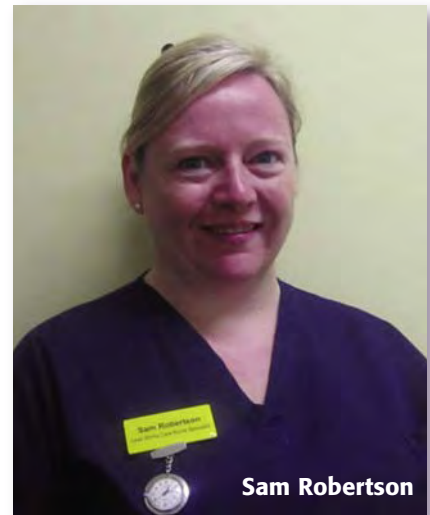
**Sue Hatton states...**This is a great step forward...we hope other stoma care nurses and GP's will call on us too – as the Colostomy Association has much to offer – people living with a colostomy – support, reassurance and practical advice.

**Irrigation Focus on Stoma Care Nurse Specialist...Sam Robertson at the Royal Devon and Exeter Hospital...**

I had been referred to the Royal Devon & Exeter Hospital by Mr. Ian Daniels (Vice-President of the Colostomy Association) and my surgeon to have a colonoscopy under anaesthetic. Staying overnight with friends having taken the train from Truro to Exeter, I arrived at their house just in time to mix my first litre of Moviprep! More about this procedure in top tips at the end of this article!

Sam Robertson came to visit me on the ward where I was waiting to go

down for the procedure. I wasn't expecting to see a stoma nurse, so it was a real surprise but a very welcome one as I was anxious and nervous about the outcome of the procedure.



Sam Robertson

Sam is half my size, but her lovely smile and warm compassionate manner as she knelt down beside me put me at ease. She had brought me a little present – a goodie bag full of different drainable bags, disposable bags and a very nifty pair of scissors – she asked me how I felt about this minor operation – it was good to talk.

Sam originally came from Shrewsbury, where she trained as a nurse 24 years ago, after which she joined the navy as a staff nurse. She has been with Royal Exeter and Devon for some 11 years and is now responsible for a team of 4 hospital and 2 community stoma nurses who see on average 25 new patients a month – patients may present with colorectal or bladder cancer, inflammatory bowel disease or functional problems.

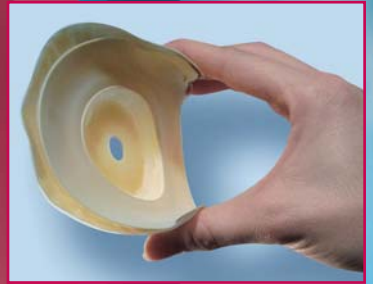
Sam's post is sponsored by Coloplast – as a stoma care nurse Sam believes in



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# Irrigation and you...

supporting and educating her patients. She does this by giving patients educational material as well as offering several different appliances in order to find out what suits them best. Each patient goes home with a choice of bags with the opportunity to change appliance type when they are seen at their 2 weekly check up.

I asked Sam if she gave new colostomates information about Colostomy Irrigation. She told me that, when there is pre-planned surgery for someone who will be having a colostomy, she tells them about the alternative options of stoma management – Colostomy Irrigation, Vitala and Conseal plugs – post surgery. She will also tell them about these options again when they are seen at 3 months and again at 12 months.

As we all know coming to terms with having a stoma is hard enough to get your head around – considering the various methods available to you around managing and coping with your stoma as the same time can be quite a pressure, but Sam continues to tell her patients all the options available to them each time they see her for a check up – quality of life for each patient being uppermost in her mind.



**Brandon Gwillam and Mark Johnson**

Recently Sam and her team promoted Colostomy Irrigation on their stand at a recent Patient Open Day held for their stoma patients. Brandon Gwillam and Mark Johnson put together an amazing 'irrigation dummy', using a

mannequin kindly donated from the hospital 'ELF' charity shop, a pond pump and coloured water. My only comment here was that I wished they had invited irrigators to come and talk at the stand too – maybe next time!



**Sue writes...** Getting back to having a colonoscopy...having put on a lot of weight since my last colonoscopy through the stoma (due to sedentary lifestyle, travelling and access to mouth watering menus!). I offer some valuable tips for those more portly persons who have to undergo this procedure!

## Top Tips - Colonoscopy through the stoma...

- Marigold Bullion makes a good hot drink between having to drink the 2 litres of disgusting Moviprep, Fleet or Picolax. Squash does help to cope with the lemon flavour, but by the time you reach for glass 8 you are ready to gag!

- Wear loose fitting clothes, as your tummy gets bloated with all the fluid intake and tight fitting waistbands are very uncomfortable.

- Wrap up warmly, as this procedure makes you feel chilled and shaky.

- You will need to wear drainable bag – so a couple of weeks before the procedure, make sure you have a new supply of drainable bags, do not rely on the ones you have stored away at home as the adhesive may not be as

powerful and the resulting leaks can be mortifying. Test them out by filling with water.

- When emptying the bag put an old jug into the sink and empty your bag into this then pour the contents away into the loo. I couldn't bend my knees to squat in front of loo and couldn't sit on the loo to empty my bag as my tummy was in the way so there wasn't enough room to release the fluid from the bag into the loo. After this hideous procedure was over I rinsed the jug with Milton fluid to sterilise it and then washed it out with hot soapy water.

- Obtain mattress covers from your supply company. However much you think you might have finished – there is inevitably a moment, during the night when there will be a nasty warm wet feeling around your nether regions.

- Put a small, old hand towel, J-cloths, Lint wipes, anything absorbent, between you and your pants/underpants to absorb any leaks. A good supply of J-cloths in your bathroom is invaluable for mop ups.

**Any more tips for coping for this procedure would be very welcome!**



## Editors Comment

Two leaflets are available from the Colostomy Association 'An Introduction to Irrigation' and 'Colonoscopy through the stoma – A patient's experience'

**telephone:**  
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# Yours Positively...

**Bonafide city gal...  
Hayley Robinson 33 is  
passionate about living life  
to the full...she loves  
shopping, hanging out  
with friends, nice meals,  
and a good glass of a  
vineyards finest...she says  
having a colostomy is  
definitely not what  
defines me...**



Ask any of my friends and they will all tell you I am a bonafide city gal, my name is Hayley Robinson I'm 33 and I love shopping, hanging out with my friends, nice meals, a good glass of a vineyards finest and own a very unhealthy shoe collection. Oh! And by the way I have a colostomy too. The reason why I began like this is because having a colostomy is definitely not what defines me!

I was born with Cloaca, which is where some of the internal organs do not form properly, outwardly you would never know I was different but underneath my clothes lies a very different story, I have had 51 anaesthetics and extensive surgery.

When I was just 17 days old I had a colostomy formed, which was subsequently reversed. However as I turned 15 years of age I had to have another colostomy and this time it was permanent. This article is about my determination to fulfil my dreams – accept my colostomy – and live life to the full!

I didn't have the best of times during my childhood, school was hard going to say the least especially during my teenage years. Accepting – an entirely different body image – as well as learning the practicalities of managing my stoma was difficult but looking back I managed to cope, study and take my GCSE's!

Having a colostomy young is hard – for me what I feared the most was never being able to fulfil my dreams or feel attractive and sexy again – I dared to hope that one day I would achieve both. My purpose in telling my story is not to share what some might deem – a sad tale – but to be able to reassure anyone (especially the young) who might be about to have or have just had a colostomy to treat life like a game of supermarket sweep, grab everything you can with gusto!

By the way, my colostomy isn't normal if there is such a thing! It prolapses and I have constant skin problems and the ongoing flatulence causes me

some embarrassing moments so please don't think I haven't suffered with it. My goodness I have had some awful times managing it!

In my mind – whatever life has thrown at me – I have always held fast to my dreams! I had two main dreams, to become a dancer and to fall in love and live happily ever after. I never considered either dream unreachable why should I, why should I be the one to settle for less than I deserve, less than everyone else! I didn't want people to feel sorry for me, I wanted a shot at what they had and granted sometimes I had to push a bit harder but no way was anything going to stop me.

I started my dance career at 20; I wasted a few years not quite knowing what direction I wanted to go in, classical etc. I approached various dance schools – taking a deep breath and giant leap of faith – as I explained what was wrong with me and said wearing a leotard would be an impossibility as it would expose my

medical condition, which I wanted to remain hidden. One dance school told me that I would never become a dancer unless I could wear a leotard! I felt hurt and angry, and thought to myself why should someone's attitude and a piece of Lycra hold me back!

I can't deny I was nervous when I approached another dance school this time it was the DM Dance Centre in Southampton where yet again I explained my situation—screwing up my eyes and waiting for the obligatory – sorry we can't teach you. This time I was pleasantly surprised when it didn't come! Marsha Brown, later to be my mentor was so kind and supportive, she understood about my problems and took me on and trained me hard just like any one else. Wearing a leotard wasn't an issue either as everyone trained in joggers and t-shirts!

The atmosphere at the DM Dance Centre was warm and supportive! I trained with them for ten years of my life and even today everyone's still there for me. I competed in several medal tests. My outfits were tailored to my shape, which was the same for everyone – black and showered with masses of decorative sparkles – I have to say no one even looked at my tummy area.

I finally found my style and dancing direction – Street Jazz – which is music video style – the market leaders at the moment are Diversity. You may remember them as in 2009 the group decided they were ready to tackle Britain's Got Talent; they blew the judges away with their dynamic and creative dance moves pulling out all the stops during their final winning performance!

It was then that I made a life changing decision to become a dance teacher! I trained hard with Marsha she was great, whenever I needed to deal with my colostomy it was never an issue and any smells were cleverly disguised by body sprays, I always managed. There was no way I was letting go of my dreams.

I did a gruelling exam in front of three examiners their eyes all focused on me, no allowances were made and I achieved top marks, I was so proud! I went on to teach at an after school club of 25 children and even dabbled in cheerleading with a squad of 12 girls. I have done a lot of show work, performed and even written and choreographed my own shows. I am currently designing a database for

primary schools so they can order choreography, which I will produce. I'm also looking to be a schools advisor helping to set up future dance clubs.

As I mentioned earlier I had two dreams, my second was to find true love, and to the girls and guys out there reading this, a colostomy should in no way inhibit you, again with determination I flung myself into city meeting and dating! Why should I miss out and settle for less than the best and the best is what I got. After meeting with a fair few Mr Wrongs, (ironically the colostomy was never the issue), I met Dean and after several dates we were all loved up. It was a few months before we got engaged and then married. We had the most beautiful white wedding! I have to say I have always enjoyed a healthy sex life and I think it is important that this is mentioned – I'm

**“Having a colostomy young is hard – for me what I feared the most was never being able to fulfil my dreams or feel attractive and sexy again – I dared to hope that one day I would achieve both...”**

glad to tell you having a colostomy makes no difference whatsoever – as most guys and girls out there aren't even bothered so when you go out on a date, don't hold back. When you do come across people who are bothered, be glad because it shows how shallow they truly are!

Not quite a month after my wedding I realised I had missed my usual monthly episode! I did a pregnancy test and Yes! I was pregnant! I was so happy! I now have two beautiful children, a two year old son called Jack, and a nine year old stepdaughter called Tiffany. Being pregnant was tough but again I got through it and boy, was it worth it! Now as a full time mum I juggle a busy social and home life but still get involved in all kinds of different projects.

I have currently headed up a Southampton parenting support group. I have also done some glamour modelling as you can see from the picture below – nothing holds me back so please don't let having a colostomy stop you realising your full potential.

Of course, I haven't gone through life alone, I have a lovely group of friends and two extraordinary special people in my life – my husband Dean who with our two beautiful children continues to make me very happy – and my best friend Michelle who is always there with a listening ear and a cup of tea even when I have the same old problems such as sore skin.

To end this piece just remember, you are a person first, and a colostomy is only a big issue if you make it one, trust me I know. Grab life, love whenever you can and never sell yourself short! Stay Fabulous!

**Hayley Robinson**



# Whose hands are WE in? The fight for our dignity...



Increasingly in these days of cutbacks the CA is hearing stories of GP's humiliating ostomates. Having a stoma is not something that does a great deal for our esteem, so it is demeaning, frustrating and frightening to be told by a GP that we are using too much of a product and that we only need to change once or twice a day. It reveals a lack of understanding and a gap in GP education. Among the many things that GPs do not know, is what it is like to be an ostomate. The majority of GPs I am sure are very considerate towards ostomates and help a great deal. But there are clearly those who are not. As ever it is the few who spoil it for the many. Of course we are facing someone who is under enormous pressure to cut costs and we are a cost. The practice manager leans on the GP. The GP leans on us. Simple.

This story is becoming more familiar by the day. Denize O'Leary has Osteoarthritis and Fybromyalgia which combined with what they think may have been ulcerative colitis has led to a colostomy. She went into hospital, eighteen months ago for a routine day surgery procedure and ended up staying six weeks and getting a bag. She has to change about five times a

day and her output varies from small nut like lumps to more or less totally liquid. We will not go into the why's and wherefore's of the product she chooses. I am well aware that standard thinking for those with a liquid output is to wear a drainable pouch. They are not my cup of tea and clearly Denize is not keen on them either. She prefers one piece closed bags. That is how she manages and that is what she likes. Now Denize will tell her story...

"I phoned the delivery company to order my regular supplies only to find that they had not received the last two prescriptions from the doctor's surgery for supply orders that I had already received several weeks before. The delivery company were having no luck getting the prescriptions from my GP and were reluctant to send me more supplies until they had received the outstanding prescriptions. This was serious. So I called the surgery, got an emergency appointment and went to see my GP. She told me that I was ordering too many bags and that such an amount (120-4 boxes) on prescription was unnecessary. I informed my GP that I used 4/5 bags a day, which would require up to 150 bags each month. But she was

insistent that I should only 'need' one bag change each day. I explained calmly that colostomy bags had to be changed when necessary and that I had no control over how many I used but her only answer was that maybe we could 'compromise' and 'settle' on 3 bags each day. She then told me that she didn't have time for all this colostomy stuff and that if I had any other queries I should make a routine appointment to discuss my needs in more detail. I refused to leave her office until she had given me the outstanding scripts for the delivery company and a script for the supplies I so urgently needed to order that day, although she insisted that I needed no more than 80 bags instead of the usual 120.

I went home and posted this incident on the CA Facebook Group. The response I got was fantastic. Everyone was outraged at the attitude of the GP. I got advice from all quarters. One person advised me to print off the 80 or so posts and comments and thrust these under the GP's nose if she didn't give me what I needed.

Three days later I was back at the GP's surgery, this time for the suggested routine appointment. I'd made it a

double appointment just to be sure I could sort things out properly without feeling rushed. By choice I was seeing a different GP, a man this time, following the unwelcome attitude of the first GP. I started by explaining that I needed to clarify which items I needed as the doctors had problems finding my ostomy supplies on the computer and this had caused problems issuing the prescriptions. I explained how many bags I used and which product had which purpose, which was met with, 'When did you last see your stoma nurse?' I replied, 'Last week, to which I was asked, 'Is she aware you are using all these products.' I informed him that she had advised me on them all, and yes I needed them all. Basically, I had the same fight all over again. This GP did not believe that ostomates needed adhesive remover, 4/5 bags a day, or security tapes. He felt that I was somehow abusing the system by obtaining and stockpiling supplies that I did not need or use. I argued that the items were neither decorative nor particularly wanted. They are a basic medical need, a necessity and although expensive, essential to my physical health.

Unfortunately he still did not get it. He likened it to people ordering support stockings and toddler's sippy cups which started to annoy me. So I then told him that whatever his views were, I was not leaving his office until every item I wanted was placed onto repeat prescription so I could order them myself online without having to refer to the GP. (We have an online prescription request where we just tick which items we need and then collect the script the next day, easy peasy). I then pulled out a printed copy of my Colostomy Association Facebook Group Posts which had pages and pages of replies and invited him to read every single one, and the amount of bags each person needed. He declined. At that point I think he realised that he knew far less about ostomies than me. His parting shot was that he expected me to obtain a letter from my stoma nurse warranting every item I had asked for. I said, 'Yeah, OK'. He's still waiting but I have my items on repeat. Job done." What an appalling way to treat a patient. What blind ignorance those two GPs displayed. They should be reported to the General Medical Council. An ostomate is incontinent, they have no control over their output,

so they have to change bags as required. No GP can state that you only need to change 'once a day'. And as for negotiating the quantity of bags, in doing so the GP is accusing Denize of lying about the number she needs. And how do we all feel if we are about to run out of products? Very nervous indeed.

These GP's are not putting the patient first, not putting the patient at ease! To say that you 'don't have time for a patient', is disgraceful. Well let's swap places with these GP's and give them a stoma each and see how they feel when we tell them they mustn't use so many products and they can't use adhesive remover! Stoma products are much more serious than 'support belts' and 'children's spill proof mugs' and it is an insult for any GP to make the comparison. The final cheap shot of the second and male GP in asking Denize to get the stoma care nurse to write the surgery a letter confirming that she requires the products is just that, cheap. As it happens stoma care nurses, when asked, will write letters confirming the supplies the patient needs.

So, now your blood is boiling, what can we do about it? Well, the first thing of course is to share the experience. Denize posted on the CA Facebook Group and gained much needed support from the rest of the members. If you are going to take on the authorities it helps to have support. Denize has since joined the Patient Participation Group (PPG) at her surgery and now they treat her like royalty. It's not right, it's not fair on the other patients but if it gets us what we need and gets them to treat us with respect, it's worth it. So perhaps we should all join in with these PPGs now, before any of our GP's try and restrict our supplies. Let's get in close, build a relationship with them. Perhaps in the process we can educate GPs about the needs of the ostomate and get them all to be more understanding.

The CA has been looking at this matter. We have tried to see if any of the Patients' Rights and Human Rights Acts and Charters actually give us the right to be prescribed what we feel we need but so far we have not found anything. You have a right to be seen by a GP and a right to be prescribed the medication he or she feels is correct for you and is within their

prescribing remit but you do not have a right to dictate the quantity. At least we haven't found anything to this effect so far. In the meantime we need to educate the GPs and if getting on to the PPGs is the way to do it, we should. Don't what ever you do, give in. If you are having difficulty ask your stoma care nurse for help. They decide what is best for us, they know how much of a product we need, they know our specific requirements. Indeed it is they who initiate the prescription process in the first place. We as their patients should be able to call on them to come to our defence. They need to make it clear to GPs that the prescriptions and the quantities that have been set by them – must be maintained. They are after all advanced practitioners in stoma care – specialist clinicians – who within their practice ensure that 'we' their patients are empowered by them to make informed choices in regards to appliances and the necessary accessories, we are also taught to care for and manage our stoma ourselves. Let's hope they are ready and willing to fight our corner!

Of course if the NHS is looking to save money in the ostomy area, getting the SCNs to offer irrigation to more patients for whom it is suitable might help enormously.

## Duncan Wells



## Editors Comment

To learn more about the **Patient Participation Group (PPG)** or to download **their communication toolkit**

e-mail:  
[admin@napp.org.uk](mailto:admin@napp.org.uk)

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# Living with the consequences of cancer treatment...

**Dr. Jervoise Andreyev MA, PhD, FRCP**  
**Consultant Gastroenterologist in Pelvic Radiation Disease**  
Royal Marsden Hospital,  
London and Sutton



The diagnosis of cancer can be devastating. The treatments are then frequently complicated with some people requiring months of chemotherapy, radiotherapy and multiple operations. The good news is that treatments are increasingly effective with twice as many people alive today after the diagnosis of bowel cancer as were surviving 30 years ago.

Many patients will require a permanent stoma. When stomas work well, most people can cope. However, when a stoma behaves badly, it can affect a person's confidence, their well being and family life. This is all so far from the popular image of cancer, which, while terrible, in the newspapers is

often reported to be swiftly, and efficiently treated, people get the "all clear" and then get on with the rest of their lives.

The surgeon who created the stoma and the stoma care nurses will give expert advice about how to overcome "mechanical" problems due to the stoma itself. However, sometimes people forget that there are other reasons why a stoma may behave erratically and be difficult to manage.

At the Royal Marsden Hospital, I am fortunate to run a rather unusual clinic, which aims to help people with difficult bowel function and nutritional problems after cancer treatments. I am a bowel specialist, my colleagues

include Clare Shaw and Lorraine Watson, senior and experienced dietitians and Ann Muls, a senior nurse and expert in symptom control. We often see our patients together. After cancer treatments, erratic bowel or stoma function is common. If the surgeon has excluded any reason related to the stoma itself then it is worth thinking about other reasons for its troublesome behaviour.

Sometimes, stomas work badly because people are not eating sensibly. Too much or too little fibre in the diet can cause problems; some people are taking vitamin or mineral supplements, which upset the guts. Drinking too much alcohol can lead to loose stool. Medicines prescribed for





## Derek Baker's experience...



Way back in April 2009 I was diagnosed with colon cancer. In order to shrink the tumour prior to surgery I was started on a regime of chemotherapy and radiotherapy. Due to a somewhat traumatic reaction to the chemotherapy it was only in December 2009 that the tumour was removed and a stoma established. In June of 2010 I was diagnosed with secondary liver cancer and in August I underwent a liver resection.

other reasons can have bowel side effects. These causes can usually be easily sorted out and we are often able to give people simple advice, which helps them.

Erratic stoma function can occur when a condition called small bowel bacterial overgrowth develops. This means too many germs have moved from the colon where they live normally (and play a vital role in keeping us well) and start growing in parts of the bowel where there shouldn't be any germs. Any bowel symptom, from constipation to diarrhoea, can result depending on which germs have moved in. Often people with bacterial overgrowth also notice they are excessively windy, their belly rumbles too much or the stool in their bag seems to be oily or fatty. Small bowel bacterial overgrowth can be diagnosed with a simple breathing test or by testing fluid, which is removed from the upper small bowel using a flexible telescope – again a simple thing to do. The right antibiotic can get rid of the germs causing the abnormal symptoms.

Another common reason for loose or fatty stool is the condition "bile acid

malabsorption" which Derek describes in his article. This causes erratic bowel function with loose stools. Sometimes loose stools are followed by periods of constipation. Some people also describe excess windiness, cramps or fatty stools. Bile acid malabsorption is frequently misdiagnosed as "irritable bowel syndrome" the symptoms are similar, but a simple SeHCAT scan - can be requested by any bowel specialist, and it is completely reliable at diagnosing this condition. Some patients with bile acid malabsorption find their symptoms are cured after being taught to eat less fat, others need medication to treat bile acid malabsorption.

Modern cancer treatments are much more effective. However, side effects are common because cancer treatments are so complicated. If your stoma behaves very erratically, starts working when you are asleep, your pouch has obviously fatty stool in it, you should consider asking for a referral to a gastroenterologist. They might be able to help you.

From December 2009 onwards I became one of the some 17,000 patients that are treated with radiotherapy to the abdomen and pelvic area. Nearly everybody gets bowel upsets during radiotherapy, but these usually settle after treatment. However, about half of all long term survivors develop on-going problems. As a member of this group I found that my bowel movements did not return to what they were before surgery; I would move from diarrhoea to constipation in a matter of twelve hours and I was having to attend to my colostomy pouch on numerous occasions during the day and night. To say that this problem controlled my life would be an understatement.

Early in 2011 the oncologist who was treating me at Mt Vernon Hospital arranged for me to meet with Dr Andreyev at the Royal Marsden Hospital in London. Dr Andreyev arranged for me to have a breath test, which indicated that there was no bacterial problem in the gut. Later that same day Dr Andreyev performed a gastroscopy and satisfied himself that all was fine in that department. He then arranged for me to have a SeHCAT scan at the Royal Chelsea and

Westminster Hospital in London a week later.

A week later and Dr Andreyev was telling me that I was suffering from a condition called Bile Acid Malabsorption. In my simple terms it means that bile is called for from the liver and the gall bladder to help with digestion: This bile travels with the food through the small intestine. At the very end of the small intestine there is a small "specialist" section of the small bowel, which extracts the bile, and, via the blood stream, returns it to the liver.

For those of us where that "specialist" section was removed when the cancerous length of the colon was removed, or where that "specialist" section was damaged by radio therapy the bile is not removed from the food. Unfortunately, or possibly fortunately for other reasons, the body does not pass bile which then tends to build up

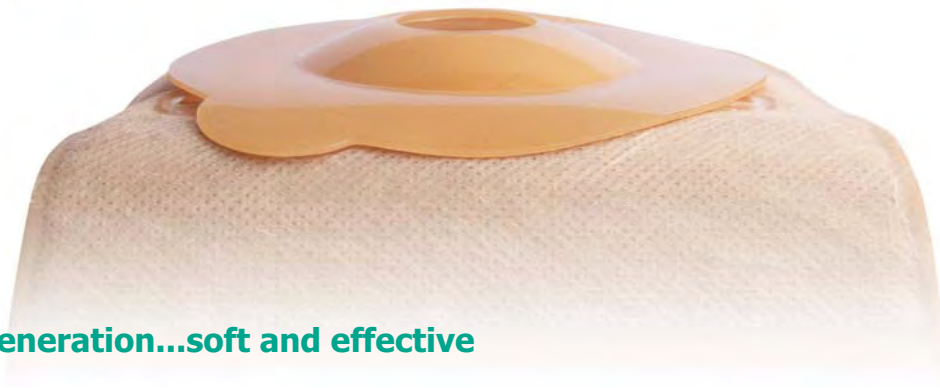
in the gut; and it is all this bile that causes all the on-going problems which makes life so miserable for so many.

Once diagnosed Dr Andreyev put me onto medication and had me talk to specialist dietitians that work closely with his gastroenterology department and are involved in the research that he and his team are carrying out. The change due to this medication and in particular the very low fat diet (the more fat you eat the more bile your body has to produce to process it) to which I was introduced was nothing short of a miracle.

Within four days of starting the diet the diarrhoea/constipation disappeared and, although I have not returned to the regularity of the pre stoma era, my stoma pouch requires much less attention during the day and only rarely at night. I have a life back again.

This dramatic improvement is solely due to unique work done by Dr Andreyev and his team. He is the only specialist in the UK specifically appointed to treat patients with damage caused to the bowels by radiotherapy. In fact world-wide there are only a couple of other gastroenterologists who have published papers in this field. The research team includes specialist dietitians, nurses and a data manager. They work closely with radiotherapy oncologists, cancer surgeons, nurses, radiographers and a wide range of professional involved in the support and care of patients who are having or have completed radiotherapy.

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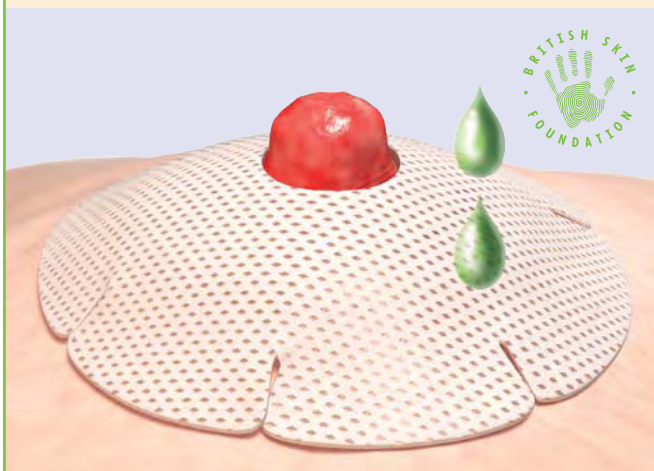
Conventional wafers can crease  
causing leaks and sore skin



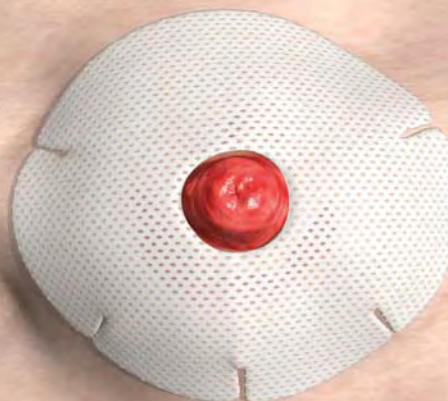
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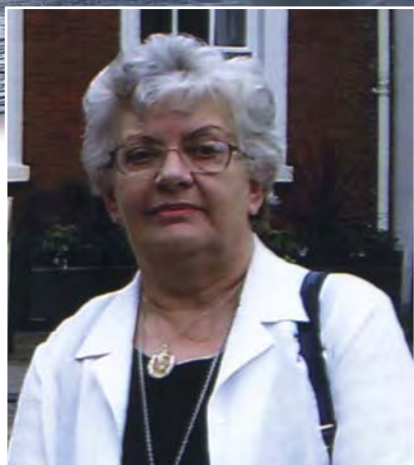


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# Going it alone...to Australia



In 2004 our youngest son and family emigrated to Australia and settled in Adelaide. When the invitation came to visit them I jumped at it! I'd had my colostomy operation three years before so I was pretty well versed in travelling with my stoma and supplies. My husband was not keen on a long haul flight so I decided to go it alone!

The first consideration was how many bags to take. I took twice as many as I normally use, plus a few extra in my main luggage; then in my hand luggage enough bags, wipes, disposal bags for the journey, spare pants, T-shirts etc. So I was booked on Malaysian Airways on Sept 29th returning October 13th 2005. I obtained all the literature available about long haul flights, got my flight socks in case of DVT and prepared for my adventure.

Our elder son took me to Heathrow. I was armed with "Choccies" – Breakaways and Kit-Kats - as

requested by our granddaughters - all things they were missing from UK. When my son said "Goodbye" and I was whisked away for boarding I felt very alone. I had been to the disabled toilet and "got comfortable" re my bag. I was seated on the aisle as requested. It was 10pm so I was tired and fell asleep as soon as we were airborne.

I was woken by the stewardess bringing hot tissues before serving a meal. There were all kinds of drinks available but I stuck to water or tea. My stoma was very quiet so I felt comfortable. I got up whenever possible and walked up and down, spent a penny, washed my hands, generally pottered around. The flight was mainly eating and sleeping and talking to my companion seated next to me who was fully conversant with all the "Gizmos" on the plane, which was a big help.

So I was still wearing No.1 Bag when we arrived in Kuala Lumpur next day. What a beautiful serene airport, very calming. My son had advised me to have a shower there. I had a three hour stopover so there was plenty of time. I couldn't find any showers so asked the gorgeous girls at the enquiry desk. They put me right and I entered a very clean, quiet annex of a hotel built onto the airport. I paid with my credit card (before I left home I had informed the bank that I would

be travelling abroad). A nice young lady gave me a huge, white, fluffy towel and showed me to a cubicle with shower, toilet, wash basin and armchair. I stripped off, bag and all, and had the most blissful shower of my life! I disposed of the contents of my bag down the toilet, tidied up and left to catch the flight for Adelaide.

I had completely lost the plot as to what day it was: all I knew was that we would get there at 6.00am. On this flight we were given a form to fill in for customs. I did my best and on arrival went through "Nothing to declare". I was stopped and my luggage searched because some suspicious looking boxes showed up on x-ray!

The suspicious packages were my chocolate gifts for the family! I should have declared them as foodstuffs. Anyway I was read the riot act about bringing such contraband into the country and I promised not to do it again.

Meanwhile my family were getting worried, as I was the last one to come through. I was greeted by lots of hugs and kisses and then off to their house for breakfast. After a shower and a bag change it was agreed that I should try and keep awake as long as possible to get accustomed to the time difference. So we all went to have lunch at a hut on the beach, had

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Cruising round Sydney Harbour...

a walk, and went on a drive round Adelaide. We had an early evening meal and I managed to stay awake until 9.00pm. Staying with the family in a bungalow with two toilets was very comfortable. It meant it was easy to do a bag change and take my time.



Cuddling a Koala...

Over the next few days we visited many beautiful places, saw some fantastic sights and ate out quite a bit. The food was delicious but one day I must have eaten something that upset me because on the journey back after a long day I began to feel something happening in my bag. It turned out to be a bout of diarrhoea. When we got home I put on a drainable bag and went to lie down. I was all right by bedtime and next day back to normal.

Halfway through my visit my son and I spent two days in Sydney. We did an internal flight and at Adelaide Airport my small suitcase showed something sharp on X-ray. So all my things were turned out and my little scissors were discovered. No amount of explanation

was tolerated and my precious scissors were popped in the "sharps" bin. How could the authorities doubt a little grey-haired old lady but it just shows how thorough they are!

When we arrived in Sydney I went to a chemist and bought some "baby" scissors with rounded ends (which I still use). We had a fabulous time! A cruise around the harbour with dinner on board, returning at twilight to see the harbour bridge all lit up – a simply wonderful sight!

Towards the end of my visit we spent the morning in Adelaide market where we had an all-day breakfast, which lasted us until teatime. Then back home – getting all dressed up, jewellery, high heels, perfume etc., ready for our evening meal in the revolving restaurant high above the city centre. This was my farewell treat to the family for their hospitality. We whizzed up to the top floor via the fast lift and had a really special meal whilst the restaurant turned slowly round – the views were amazing. By the time we got to the coffee and mints it was nearly dark – Adelaide was all lit up beneath us – an unforgettable experience.

On my last day we were in a café at the airport having a farewell meal when it was announced that my flight was the last one to leave from this terminal as the new one was being opened next day. So in departures we all sang "Auld Lang Syne". I boarded after lots of hugs and tears and a last glance at my family after a very memorable holiday.

**Mavis Cordon**

## Top tips for a smooth transit through airport security...

### Before you leave home:

- Obtain a travel certificate from CA and get it signed by your doctor and stamped with the practice stamp.
- Make sure you take the tear-off portion of your prescription which lists the stoma supplies which you can obtain on repeat prescription, and/or obtain a letter from your doctor confirming that you have a stoma and you will be carrying medical supplies.
- Put stoma supplies inside clear plastic A4 zip folders and pack in your hand luggage.
- Pack anything that might look suspicious when it appears on the luggage X-ray machine in your "check-in luggage" which goes in the hold. This includes scissors, containers of over 100ml liquid, aerosols, small sachets of gel etc.
- Don't wear any metal objects likely to trigger the scanner i.e. jewellery.

### Before going through security:

- Change or empty your pouch in the disabled toilet at the airport.

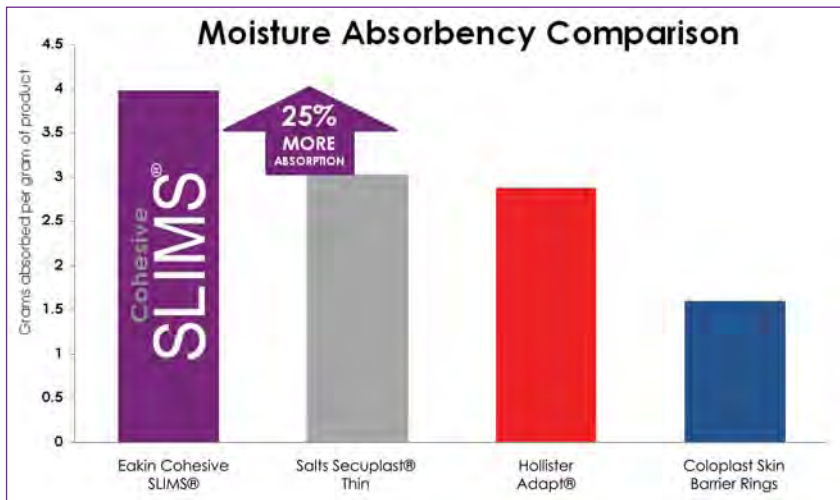
### As you go through security:

- Fold the travel certificate open at the page in the language of the country you are in.
- Have your travel certificate in your pocket (not your handbag which will be on the conveyor belt).
- Have a spare bag, wipes and a disposal bag in your pocket just in case.

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# 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 hope you can help with my problem regarding my GP and my supplies.

Since I have had my colostomy I have been ordering 3 boxes of pouches for a two part colostomy system- this has been over a decade. My doctor has contacted my supplier (Home-style in Medway and Dartford) and said I only need two boxes of pouches a month. However I change 3 times a day, more if I am going out in the evening, as a colostomy is enough to contend with without worrying about lumps under clothes and full pouches while out.

This is not the first time my Doctor has queried the amount I use, although my Consultant said not to keep a flange on for over 24 hours as my skin was reacting very badly my GP felt this was unnecessary and local stomas nurse of the time said I should use one piece system. This I did try but I ended with torn and damaged skin, which did not completely heal for several months. It was a real problem and they did agree to a two part system.

I do admit I am very fat and my abdomen does have areas where it goes in and out. Also I had an emergency unplanned colostomy and ended up with a large fistula adjacent to stoma, which means the total width of my stoma is only covered by 70mm flange/pouch.

Is it unreasonable to change as often as I do? Also if I start to leak then I have to change the flange and then also have a new pouch, as who would put a dirty soiled pouch onto a new flange?

Personal hygiene is very important when coping mentally with a colostomy, and each time I order equipment I expect him to query it. I am over 60 so I do not pay for supplies. I also take a drug at the moment as part of my treatment for breast cancer and my GP is querying why I want one over the other, which I am taking this up with my Oncologist in two weeks time, but I feel that it is indicative of his attitude to supplying equipment and drugs.

If he sticks to only 2 boxes a month i.e. 60 pouches do I please have any redress to put before the PCT?

I am sorry to enter into such personal detail with you, but I feel I have nowhere else to turn.

Yours faithfully,  
J.J.

## Dear Editor

Since I had the A.P.R. (abdomino-perineal-resection, I think!) operation for an anal cancer in 2004 I have, apart from the first three months and this last year, tried to irrigate every other day. Last year, in March I had another different kind of cancer removed from behind my stomach, which involved the removal of a little more of my already truncated colon.

Since this last operation I've notice two big changes in my body. One is I.B.S., which often 'interferes' with the irrigation timetable – diarrhoea renders it unnecessary! But the other is more unexpected, and that is eczema. Eczema has now spread from my hands, where it started after the first bowel op, to my legs and now my neck and arms.

I noticed in a recent health questionnaire from, I think, a

colostomy-related organisation that, in amongst the questions was one asking about the onset of eczema after the op.

Has anybody else reading 'Tidings' as a colostomate gone on to develop this annoying condition? And if so, can anyone tell us why? And how best to control it – for example, no dairy products? Is live yoghurt any help?

Yours.  
H.C. (Mrs.)

## Dear Editor

The advice given on the 'Dear Nurse' page in the Spring edition of Tidings to your correspondent who had problems with sore skin around a recently formed stoma is much the same as I received when I had a similar problem in the early days of my colostomy. I had red, sore and itchy skin under the wafers of the several types of pouch that I tried – the action of removing a full pouch seemed to tear off the skin surface, and I needed medical adhesive remover to get them off anyway. I applied skin barrier wipes, but the resulting plastic film had to be removed frequently as it cracked, and the medical adhesive removers needed for that too made my skin even more sore. It seemed a vicious circle.

Then one of my stoma nurses told me to stop using skin barrier wipes, and just apply a barrier cream before applying a pouch – several makes are available; I mostly use Opus Healthcare's La Vera. That completely solved the problem, and I have had no trouble at all with sore skin over the 2 years since. I simply remove the old pouch, clean up with (preferably warm!) water, pat it all



# Readers' writes

dry, rub lightly in with a finger a small pea-sized blob of barrier cream from a tube, blot off the excess with a dry wipe leaving just a little moistening of cream on the skin, and stick on the new pouch. It won't adhere as strongly as onto bare skin – and one can pull off and re-position the pouch if needed, which can be very helpful – but hold the pouch on for a few minutes, and it will stick firm. The barrier cream is remarkable stuff, not at all greasy, and pouches do stick on after it has been applied. When you come to remove the pouch later, it will peel off more easily without stripping the skin. The residue on the skin washes off readily with water, needing no adhesive remover – and no more sore skin.

If one is troubled with leakage, this may not be the solution for you, but I strongly recommend your correspondent to give it a try.

And thanks for your and all the staff's efforts in bringing out Tidings – it's a real tonic to read it, every word; it just makes me realise how lucky I am with my own simple, manageable colostomy (which came about as I had prostate cancer ... but that's a story in itself).

Best regards,  
P.R.

## Dear Editor

Referring to one of the letters from Readers in the Chatback section of the Spring issue, I would certainly endorse Mrs. H.C.'s Christmas wish for a drainable bag with a VELCRO opening at the top also - what a brilliant suggestion - enabling OSTOMATES to flush and clean the bag and more importantly I feel provide an easy way to release the

build up of gas without having to empty the bag each time. After an operation for a twisted bowel, which became gangrenous I had an ileostomy in 1996. I was supplied with a drainable pouch (OMNI ILEO) with a clip at the bottom for draining and a button at the top, which could be removed to allow the gas to escape easily and cleanly. I used this make of pouch with great success and was devastated to learn a few years ago that this product had been withdrawn. This must have been a big disappointment to many users.

Since then I have tried every make of pouch available and none of them allow the user to release the gas without having to empty the bag which, of course, means that the user has to be in a toilet which at times is very inconvenient. Therefore, to have a pouch with a top opening would be marvellous and make life much easier for most Ostomates. I hope and trust that Tidings can help with this important matter and perhaps persuade some manufacturer to produce such a pouch so I do hope that this suggestion will reach SANTA and his workshop and will give this idea sympathetic consideration.

Yours sincerely,  
R.R.M.

**From Ed:** I agree it's always the same just when you find a design that suits your needs – research and development want to change it for the better. Is it for the better...? Sometimes it's a step backwards. As with other products – please manufacturers get feedback first before you enhance or change something that works really well for people!

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

The Colostomy Association strives to challenge and change public perceptions that only a certain sector of the population is 'living with a colostomy' in this issue of Tidings – we focus on the care of the very young...

## Looking after the little ones...

Claire Bohr

Paediatric Stoma and Bowel Management Nurse

Bristol Royal Hospital for Children

Many people are not aware that babies, young children and teenagers have medical conditions that require them to have stomas. Unlike adult ostomists the majority of paediatric patients have their stomas as a temporary procedure and this can be anything from a few weeks to several years. This is dependent on the child's medical condition, the child's age, and the individual practice of the surgeon.

There are two reasons why any stoma is formed;

1. To bypass faeces with a stoma to minimize the risk of leakage through a join that has been made surgically in the intestine or the rectum. Or
2. To create an outlet for waste matter to pass through the digestive system.

During Pregnancy most women have two scans one at 10-13 weeks to estimate the date of delivery and another at 20 weeks to check the baby is growing as expected. It is very rare that a scan will be able to detect conditions that will require a stoma, although other conditions involving the developing intestine can be diagnosed prenatally.

The most common causes of a baby requiring a stoma are:-

- Perforation of the intestine
- Malformation of the anal canal, which can be, either there isn't an opening in the bottom or that the bottom hole has not opened in the correct place.

The most common cause for intestinal perforation in premature babies is Necrotising Enterocolitis (NEC). This is when a combination of factors damage the baby's immature gut leaving it exposed to harmful bacteria. This may result in a lack of blood supply to any part of the intestine



causing it to weaken. If it is not treated immediately with intravenous antibiotics the intestine may die and eventually perforate leaking faecal matter into the baby's abdomen. Because these babies are premature they are usually still being cared for in hospital when this condition occurs. The baby's tummy may become enlarged, they may be sick and their condition will deteriorate.

If a perforation is suspected the baby will need emergency surgery. This may involve just mending the perforation or removing a length of the affected intestine. In either case the baby will usually have a temporary stoma to bypass the faeces away from the intestine that has been operated on.

Anorectal malformations (imperforate anus) occur during the 5-7 week of the baby's development in the womb, the exact cause is still unknown. It occurs in 1 in 4,360 live births and there are several variations of this condition:

- The anal passage may be misplaced and not line up with the rectal muscles.
- A membrane may be covering the opening in the bottom. The rectum may not have grown long enough to join up to the bottom.
- The rectum may join up with the urinary or reproductive system.

Depending on the variant and the surgeon's preference the baby will require either one or three operations over a period of time to correct the malformation. Initially a stoma is formed for an outlet of the faeces. Every baby born in the UK must have a newborn baby check between 4 and 48 hours after they are born. This is usually carried out by a baby doctor who checks the baby from head to toe looking for any abnormalities. Unfortunately this condition is not always picked up at this check as many of the babies' bottoms look normal (except for the absence of an



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opening). Increasingly, mothers are only staying in hospital for the minimum amount of time after delivery (6-8 hours after having the baby). This is not always long enough for the baby to have had its first bowel motion, so problems may not occur until the baby has gone home. Also with developing technology temperatures can now be taken using ear thermometers, anal malformations were seldom missed when midwives used rectal thermometers.

The majority of babies that have surgery requiring a stoma do so as an emergency therefore little or no preparation is possible for the parents from the stoma nurse. Not all centres are fortunate to have a stoma nurse on hand either before or after the baby has had a stoma formed. It is then up to the hospital nursing staff to support the parents during this stressful time.

There are only approximately 15 Paediatric stoma care nurses in the UK. These are predominantly based at the designated Childrens Hospitals where a large proportion of the operations take place.

It's important that parents of premature/sick babies are involved in their baby's care as soon as possible. These babies will have several tubes attached to their tiny limbs, probably on a breathing machine and cocooned in an incubator. Very premature babies can become distressed when they are disturbed so "minimal handling" can be an instruction attached to the incubator. For a parent this can be distressing as the natural reaction is to hold your baby close and kiss it better. As soon the baby is stable enough I encourage parents to learn how to care for the stoma, this will give them a sense of importance and a parental role, and with the large numbers of nurses on one unit it will provide continuity of the stoma care.

Premature/small babies can spend several months in hospital before being ready to go home. This enables the parents to become confident in caring for the stoma before they have to take their vulnerable baby out into the big wide world.

Premature and new babies have very fragile skin that can easily absorb chemicals, so it's important that the products used are "baby friendly". This is where the expertise, knowledge and experience of a paediatric stoma nurse are invaluable. The range of stoma bags for babies has increased over the last 10 years and before

these were available the only option was to use small adult bags, at times the bags were bigger than the baby. Bags are now available in one and two piece, some have printed covers to make them more appealing for the small child. It's now possible to get tiny support bands and brightly coloured girls and boys pants to give support and protection from tiny fingers that always seem to want help when changing the bag!

The support each family receives once they are home varies greatly dependent on the resources of each hospital. Some paediatric stoma nurses will have the resources to do home visits; some areas rely on "adult trained stoma nurses" to continue the care in the community with regular communication with the paediatric stoma nurse. Some areas have community paediatric nurses who will visit the family.

More commonly, mothers take maternity leave and return to work so stoma nurses are required to teach nursery workers, grandparents and other relatives how to care for the babies stoma. It's not always easy to find babysitters who are happy to look after babies with stomas so quite often parents don't get any time to themselves.

Paediatric stoma nurses try to put parents in touch with other parents who have babies with a stoma; this makes them feel less isolated and able to share tips and experiences. There are both local and national support groups that parents can contact for continuing support.

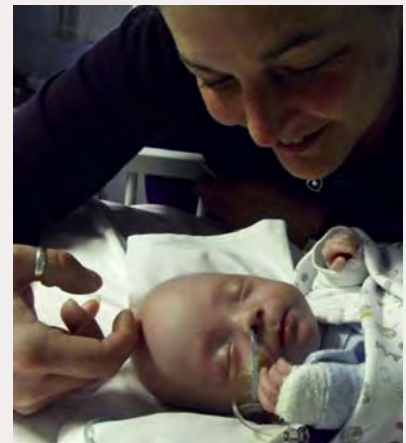
Parents are encouraged to treat their baby no differently than if they didn't have a stoma and they should be able to have a normal diet. Some babies who have lost a long length of intestine may need to be on a special milk to help them absorb nutrients to grow. Parents are told to be aware of their babies stoma output and if the baby has very loose stools they can lose essential electrolytes and become dehydrated within hours, unlike adults who are advised to take a rehydration fluid, it is recommended that parents seek medical advice immediately.

There should be no reason why babies with stomas can't be dressed in ordinary baby clothes, sit in a car seat or pushchair and receive lots of cuddles.

As a paediatric stoma nurse caring for babies with stomas can be challenging: trying to find space on tiny tummies to stick bags on, getting

it to stick for 24hours, stopping babies pulling at them, and preventing delicate skin becoming damaged. But it also has many more rewards: watching parents grow in confidence with each bag change and saying goodbye as they finally leave the hospital, which in some cases may have been months. And it's not always goodbye as many children are followed up by the hospital for many years after their stoma has been closed to ensure they are developing normally.

### Parent comments...



**From Zac's Mum...** "I grew to love my baby's stoma as it was part of him. I enjoyed learning and nursing him too. It was certainly more tidy than changing a dirty nappy! At one point the stoma nurse mentioned the stoma size shrinking, but just the opposite happened on my premature baby, as he grew so did his stoma!"

**From Adam's Mum...** "I didn't think I would be able to cope with changing the stoma bag on a wriggling baby but once I got used to it, it was easier than changing a nappy."

**From Daniel's Mum...** "I was shocked at first to see the stoma on my baby's tummy, but I knew I had to learn how to look after it so I could take him home"

**From Thomas's Parents...** "We stayed for 3 months in the hospital and were shown how to change the bag by the stoma nurse, we felt that we could do something towards his care."

**From Mollies Mum...** "The stoma nurse said I would learn how to change the stoma bag, I didn't believe her, but she gave me confidence, and she was right."

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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 been experiencing pain in my back passage and the feeling of wanting 'to go'. I have experienced some constipation and I am still in pain on and off. I take paracetamol for the pain, which has helped briefly. However whilst experiencing the pain my stoma went as flat as a pancake and I must say I am concerned about its 'flatness' is it normal. Could you tell what could be causing the pain and why my stoma is behaving oddly?*

**A:** I presume you still have your rectum (back passage) in place. The cause of the feeling of needing to go to the toilet via this route is common and can be due to a mucous plug in the rectum. An easy way to deal with this, once it has been confirmed as the cause by your GP/Consultant, is to have a glycerine suppository inserted by the District Nurse. This should soften the mucus and allow it to be passed more easily. You say you are experiencing constipation, I presume you mean via the colostomy? It is not uncommon for colostomies to get constipated, especially if there has been a change in diet or amount of fluid intake and this can alter the shape of the stoma. I would suggest increasing your fluid intake to 1.5-2lts per day and eating foods which you know help to soften your stool. If medication is needed things such as Lactulose, Fybogel, Senna etc are useful. Speak to your GP or Stoma Care Nurse first.

**Q:** *I have had a permanent colostomy for 10 years due to bowel cancer so have regular colonoscopy appointments. I recently had problems associated with taking Picalax prior to a colonoscopy, although I was given information about the colonoscopy procedure it*



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.

*didn't prepare me for what actually happened. Over a 24hr period my bag over flowed some 6 – 8 times as you can imagine the experience was extremely distressing, embarrassing and messy for me and for my family. I soon realised my usual stoma bag was totally inadequate as it just couldn't cope with the quantity of output coming from my bowel. I am concerned that no suggestion or provision of a different bag is offered to those of us who have to cope with this examination on a regular basis – a bag with a larger capacity that is drainable for times such as this would be so helpful. In my endeavour to help myself I contacted Fittleworth my*

*supply company and explained my plight I am delighted to be able report that I was sent a Dansac 815 - 15 that proved to be excellent. (I did try other samples but this one was the best) From then on I had no further problems and was able to drain off the contents of the bag easily and perhaps more importantly with no mess. As my colonoscopy examination occurs every 2-3 years can you please advise me on how I can obtain a small number of these bags for future colonoscopy examinations and could you provide me with a few tips that might be useful prior to a colonoscopy – many thanks.*

**A:** It is down to individual hospitals and gastroenterology departments to provide literature explaining the colonoscopy procedure and it should include information regarding bowel preparation for patients with stomas where necessary. It is common to use a larger pouch as per the one you have suggested, although there are many available and these can be added onto your prescription to send via your normal route for obtaining your usual equipment.

**From Ed: The Colostomy Association has an in-depth leaflet available called 'Colonoscopy through the stoma' – a patient's perspective. To obtain a copy simply contact the office on: 0118 939 1537 or email: [cass@colostomyassociation.org.uk](mailto:cass@colostomyassociation.org.uk)**

**Q:** *I have a colostomy and have been used to dealing with my supplies. Recently some items on my prescription have been queried by my GP as unnecessary along with the number of stoma care bags I use. I find this quite distressing and can't understand why this is happening. Is there anything I can do about this and who can I ask for help?*

**A:** This is a common question from GPs especially as they are becoming more financially aware. I often see patients for equipment reviews as some patients are still having equipment they no longer require. It may be worth speaking to your Stoma

Care Nurse to ask for a review of what you currently use and then she can do a report for the GP, which should reassure him that your order is still needed.

**Q:** *I had my colostomy three years ago due to bowel cancer I am worried about my family members. I understand there is a screening programme in place, and that bowel screening kits are sent out every two years to people aged 60-69 and those who are 70 can be request a kit by phone. I am concerned that my children could inherit bowel cancer via my/their genes is this possible? Is there a test for this or can they be screened earlier?*

**A:** You need to discuss with your GP/Consultant the possibility of there being a genetic link to your cancer diagnosis, not all cancers are genetically linked dependent on the age at which you are diagnosed and also a family history. If it is felt necessary you can complete a genetic family history questionnaire, which is then sent to the local genetic unit and they will calculate your family's risk and advise accordingly with regards to screening.

**Q:** *My husband has had a colostomy for several years. Lately I have noticed there seems to be a constant smell that I find rather nauseating. I have not said anything to him, as it is a sensitive issue. However we are due to go on holiday shortly with a few friends and I am so worried. I wonder if there could be anything causing the smell –change in diet or medication – perhaps you can put my mind at ease, here's hoping.*

**A:** There can be many reasons for a smell from the stoma, including a dietary or medication change and this can be a good indicator for finding the cause. If no specific cause is found it may be a product fault, for instance a small leak or a filter fault. If the filter is the cause you would need to contact the manufacturer and send them a sample of the pouch for testing. If they find a fault the manufacturer will recall all the products and replace them with a new batch. If the pouch is leaking then obviously you need to identify the cause of the problem and this may involve a visit to see your local stoma care nurse who can investigate and advise accordingly. Some patients inform me that they use drops in their pouches to mask odours and even put aftershave or perfume on the pouch cover to provide peace of mind, although I would still advise investigating the cause initially rather than masking the problem.

**Q:** *I have recently been fitted with a support garment due to a hernia. However now I find I am having problems with my bag as every time I move around – the bag comes off even though I have the support garment in place. Could you please let me know what I can do to stop this happening?*

**A:** You do not say who measured you for your support garment and who supplied it. I would suggest asking for a review as the cause may be due to the garment not fitting correctly and it may involve a small adjustment. If this is found not to be the case I recommend a review by your local stoma care nurse to investigate the cause and offer alternatives.

**Q:** *My father is 76 and has been in hospital for 3 weeks. He was admitted with a bowel obstruction and after two major operations he now has a colostomy. As you can imagine this has been a total shock to him and to my mother. My concern is how my father will cope, as at the moment he can't bear to look at his stoma or change his bag. Please can you advise on whether he will come to terms with the shock and whether there is anything I can do to help him accept his colostomy.*

**A:** When surgery is done as an emergency there is often little or no time for the Specialist Nurse to prepare the patient psychologically and therefore it can take longer for the patient to learn to accept the stoma. From my experience, although this can take time, often weeks and months, with intense input from the specialist your dad should eventually become able to manage his stoma himself. It could be worth the family members talking to the stoma care nurse to see if there is the possibility of you becoming involved, in the short term, with helping your dad to do the practical job of changing the stoma pouch. It may also help to ask the stoma care nurse to introduce your dad to one of the local Colostomy Association visitors as they can be a great inspiration to new ostomates, demonstrating that a normal life is possible with a stoma and supporting new patients with many aspects of their rehabilitation.

## 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 left hand side. The output from some colostomies may be fairly liquid particularly if only a small amount of colon remains. Therefore some colostomates may prefer to use a drainable bag.

---

## Editors Comment

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

If so write in and tell us:

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

or e-mail your query to:  
[editor@colostomyassociation.org.uk](mailto:editor@colostomyassociation.org.uk)



## Can you help OstomyAid?

**What is OstomyAid?...**OstomyAid is a project set up by the charity Ostomy Lifestyle in 2010 with the aim of gathering unused stoma bags and supplies from across the UK to put to good use in developing countries. OstomyAid provides vital medical appliances to people who would normally be unable to receive them and at the same time is reducing landfill in the UK.

A few years ago Ostomy Lifestyle often received queries from people who have leftover ostomy supplies and did not want them to go to waste. At the same time, Ostomy Lifestyle was told of the hardship many people with a stoma faced in developing countries because of the lack of stoma supplies; one example given was of people taping empty coffee jars or carrier bags to their abdomen to collect their faeces or urine. These two situations led to the creation of OstomyAid and since its inception OstomyAid has provided more than £1,000,000 of stoma supplies to people in Eastern Europe, Asia and Africa.

**How does OstomyAid work..**On a daily basis Ostomy Lifestyle receives donated items for OstomyAid; this can range from small packages delivered by post, a number of carrier bags delivered personally to several pallets of boxes delivered by a large lorry. Donations can come from individuals, support groups, stoma care centres and manufacturers of stoma care items. We are also very grateful to the industry representatives who kindly collect donated items from hospitals



and bring them to the Ostomy Lifestyle office. We are pleased to receive all kinds of stoma care items, but would ask that syringes and drugs are not sent for OstomyAid.

**We are grateful to everyone who takes the time and trouble to donate to OstomyAid.**

Once donated items reach Ostomy Lifestyle's office, they are sorted by category, repacked in bags so as to

minimise transport costs and boxed ready to be dispatched. OstomyAid operates with extremely limited funds; hence wonderful volunteers do the sorting and packing of donated items. This year Ostomy Lifestyle's landlord Reedspace have kindly helped with the provision of additional office space for OstomyAid.

**Wonderful volunteers sort and pack donated items at Ostomy Lifestyle's office in Bracknell**

To get OstomyAid supplies to where they are needed Ostomy Lifestyle usually partners with other charities. Partnering charities work in a range of different countries and ways, some have relationships with government health departments whilst others have close working ties with hospitals or hospices. On rare occasions a case is made to support a particular individual in distress, in these circumstances Ostomy Lifestyle funds the distribution of donated items.

One such gentleman, based in Cape Town, came to our attention a couple of months ago with a heartfelt plea to help him out. Hannes was paralysed, following an accident when only 18 and after many complications with pressure sores also had a colostomy formed to prevent further septic wounds.

Hannes survives on a limited income and is helped by his aging mother with cleaning and dressings. "Good gosh, nobody told me what a problem it would be to get stoma bags every month! The State only allows hospitals





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to give us 10 stoma bags a month and after washing a bag twice, the smell stays in the material and is it embarrassing to wear a third time! I cannot afford to buy the stoma bags from private pharmacies because it costs R1395.00 a box" (his income from the State is R1200.00 per month). On top of this Hannes points out that the 10 bags a month is only given when they are available as the hospital supply is often sporadic.

**After washing his stoma bags twice Hannes found the smell stays in the material and it is embarrassing to wear a third time**

Hannes offered to make a contribution toward shipping, but fortunately we were able to send stoma bags without having to accept his offer.

Hannes was ecstatic saying "You are an angel and I REALLY, REALLY appreciate your kindness and help! ... I really appreciate your effort in trying to help me".

Some of the first countries to receive OstomyAid include Ethiopia, Ghana, Kosovo, Malawi, Nigeria, Pakistan, The Gambia and Uganda. In the last month donated items have been sent to people in need in Albania, Egypt and Moldova. The charities we work with are telling us of new areas of need, so expect this list of countries to expand.

#### How can you help OstomyAid?

There are several ways you can help OstomyAid:

- If you have any unused ostomy supplies to donate to OstomyAid please send them to Ostomy Lifestyle at the address above or contact us for other delivery options.

- If you have worked with charities, hospitals or hospices in developing countries where there is a need for stoma supplies, please contact us by email at [admin@ostomylifestyle.org](mailto:admin@ostomylifestyle.org) or phone Ostomy Lifestyle on 0118 324 0069 and ask for Marian or Lynn.

- If you would like to give some time to help sort and pack donated items for OstomyAid in the Bracknell office please phone Ostomy Lifestyle on 0118 324 0069 and ask for Marian or Lynn.

- If you would like to help fund the work of OstomyAid please send donations to Ostomy Lifestyle at the address below or donate online at [www.ostomylifestyle.org](http://www.ostomylifestyle.org).

Anything you could do to help OstomyAid help more people in developing countries to live with a stoma would be greatly appreciated.

#### How to contact...

OstomyAid (Ostomy Lifestyle),  
4 The Courtyard,  
Bracknell,  
Berkshire RG12 2XB  
Telephone: 0118 324 0069  
Email: [admin@ostomylifestyle.org](mailto:admin@ostomylifestyle.org)



## Helpful Ostomy Support Groups & Organisations...

- IA The Ileostomy and Internal Pouch Support Group  
Freephone: 0800 0184 724  
[www.iasupport.org](http://www.iasupport.org)
- UA Urostomy Association  
Tel: 01889 563191  
[www.urostomyassociation.org.uk](http://www.urostomyassociation.org.uk)
- IOA International Ostomy Association  
[www.ostomyinternational.org](http://www.ostomyinternational.org)
- Gay Ostomates  
Email: [brian@gayostomates.org](mailto:brian@gayostomates.org)  
[www.gayostomates.org](http://www.gayostomates.org)
- Stomadata & Stomafr  
[www.stomadata.com](http://www.stomadata.com)  
[www.stoma.fr](http://www.stoma.fr)
- Macmillan Cancer Support  
Tel: 0808 808 00 00  
Mon - Fri: 9am - 8pm  
[www.macmillan.org.uk](http://www.macmillan.org.uk)
- Crohn's and Colitis UK  
Tel: 0845 130 2233  
[www.nacc.org.uk](http://www.nacc.org.uk)
- The Gut Trust  
(Irritable bowel syndrome)  
Tel: 0114 272 3253  
[www.theguttrust.org](http://www.theguttrust.org)
- Bladder and Bowel Foundation (B&BF)  
Formerly Incontact and Continence Foundation  
General enquiries: 01536 533255  
Web: [www.bladderandbowelfoundation.org](http://www.bladderandbowelfoundation.org)
- Bowel Cancer UK  
Tel: 020 7381 9711  
Email: [admin@bowelcanceruk.org.uk](mailto:admin@bowelcanceruk.org.uk)  
Web: [www.bowelcanceruk.org.uk](http://www.bowelcanceruk.org.uk)
- Beating Bowel Cancer UK  
Tel: 08450 719300 (Lo Call rate)  
Web: [www.beatingbowelcancer.org](http://www.beatingbowelcancer.org)
- Ostomy Lifestyle  
Tel: 0118 324 0069  
Email: [admin@ostomylifestyle.org](mailto:admin@ostomylifestyle.org)  
Web: [www.ostomylifestyle.org](http://www.ostomylifestyle.org)

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| Dietary Advice         | <input type="checkbox"/> | Travel Passport                      | <input type="checkbox"/> | World Assist Alliance | <input type="checkbox"/> |

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# Stoma Care Open Days...Join in...

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

## Coming up very soon...

**Title:** Dansac Voice Roadshow  
**Venue:** Millennium Centre, Bute Place, Cardiff Bay CF10 5AL  
**Date:** July 18th 2012  
**Time:** 9.30am - 16.30am  
**Organiser:** Dansac

**Title:** Pelican Healthcare Exclusive Coffee Morning  
**Venue:** The Board Room - Royal Botanical Gardens, 10a Inverleith Row, Edinburgh EH3 5LR  
**Date:** July 18th 2012  
**Time:** 10am -12noon  
**Organiser:** Pelican Healthcare

**Title:** Salts Healthcare Open Day  
**Venue:** Apex Hotel, 1 West Victoria Dock Road, Dundee DD1 3JP  
**Date:** July 20th 2012  
**Time:** 11.00am to 2.00pm  
**Organiser:** Salts Healthcare

Request from...

**Anna Brewer Clinical Nurse Specialist, Coloproctology/Stoma Addenbrooke's Hospital NHS Cambridge.**

We are arranging an **Open Day** on the **22nd September 2012** at **The Hexagon - Frank Lee Social Centre at Addenbrooke's Hospital, Cambridge CB2 0QQ.** We would like to **invite patients to attend between 10.30am - 3.00pm. Come and join us refreshments available.**

Request from...

**Fiona Anscomb, Caroline Read and Anna Wallace Clinical Nurse Specialists, Medway NHS - Medway Maritime Hospital, Gillingham.**

We are arranging our two yearly **Open Day** on the **16th October 2012** at **The Commissioners House - The Historic Dockyard, Chatham, Kent ME4 4TZ.** We would like to **invite patients to attend between 10.00am - 2.00pm. Come and join us!**

**Open day events are posted on the Colostomy Association website throughout the year... visit: [www.colostomyassociation.org.uk](http://www.colostomyassociation.org.uk)**

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### For more information:


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 Freephone: 0800 389 3111  
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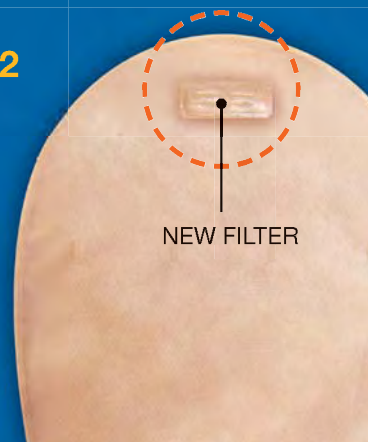
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## Doctor-speak translated...

### Do you have an 'End colostomy', or a 'Loop Colostomy', are you 'Double Barrelled'? What's a 'Hemi-colectomy', a 'Total-colectomy', a 'Hartmann's procedure', a 'Fistula', an 'Anastomosis'?

Medical professionals are very good at bandying about terms when in conversation with us – they often assume we know what they are talking about? Sometimes, of course we do but not always, so Tidings will be running a section called, 'Your Medical Directory' which explains the procedures and terms associated with our condition – that although we may nod our heads in agreement we don't always fully understand.

For an alphabetic glossary of terms visit the Colostomy Association website:  
<http://www.colostomyassociation.org.uk/index.php?p=142&pp=3>

We hope from the way we have laid this out that you will never come across a term that you have not already been given the meaning of. For example when discussing a colostomy it would be useful to understand – the terms... gastrointestinal tract, anastomosis and stoma. So off we go....

**Anastomosis** – An anastomosis is a surgical connection between two structures. It usually means a connection that is created between tubular structures, such as blood vessels or loops of intestine. For example, when part of an intestine is surgically removed (resected), the two remaining ends are sewn or stapled together (anastomosed), and the procedure is referred to as an intestinal anastomosis. And the name for the type of anastomosis will depend on the parts being joined. For example colon and rectum would be a colorectal anastomosis, whereas small bowel and colon would be an ileocolic anastomosis.

**Stoma** – is a surgically created opening that can be made almost anywhere in the body. There are many kinds of stomas. For instance, an opening into the trachea for breathing is called a tracheostomy, an opening into the stomach for feeding is called a gastrostomy and so on throughout the body. Our types of stoma involve bringing out a portion of the bowel or urinary system to create a stoma called a colostomy, an ileostomy or a urostomy.

**Gastrointestinal tract** –The gastro intestinal tract refers to the stomach and intestine and sometimes to everything from the mouth to the anus. the gastro intestinal system is essentially a long tube running right through the body, with specialised sections that are capable of digesting material put in at the top end and extracting any useful components from it, then expelling the waste products at the bottom end.

**Fistula** – A fistula is an abnormal tunnel connecting two body cavities (such as the rectum and the vagina) or a body cavity to the skin (like the rectum to the outside of the body). One way a fistula may form is from an abscess - a pocket of pus in the body. The abscess may be constantly filling with body fluids such as waste or urine, which prevents healing. Eventually the fistula breaks through to the skin, another body cavity, or an organ. Fistulas are more common in Crohn's disease, ulcerative colitis and diverticulitis  
 Waste Poo, stool, faeces

**Colostomy** – A colostomy is a surgical procedure in which a stoma is formed by drawing the end of the large

intestine or colon through an incision in the front of the abdominal wall. This opening, in conjunction with the attached stoma appliance, provides an alternative channel for waste to leave the body. A colostomy may be reversible or irreversible depending on the circumstances. Mostly colostomies will be sited on the left hand side of the abdomen.

**Ileostomy** – An ileostomy is a surgical procedure in which a stoma is formed by bringing the end or loop of small intestine (the ileum) out onto the surface of the skin. As with a colostomy this opening in conjunction with the attached stoma appliance provides an alternative channel for waste to leave the body. Ileostomies are usually sited above the groin on the right hand side of the abdomen.

**Urostomy** – A urostomy is a stoma for the urinary system. Either a section at the end of the small bowel (ileum) or at the beginning of the large intestine (cecum) is surgically removed and relocated as a passageway for urine to pass from the kidneys to the outside of the body through a stoma.

#### Types of Colostomy:

**End colostomy** – The functioning end of the large intestine (the section of bowel that remains connected to the upper gastro intestinal tract) is brought out onto the surface of the abdomen, forming the stoma by cuffing the intestine back on itself and suturing (stitching) the end to the skin. The distal (the bit that is furthest away) portion of bowel (now connected only to the rectum) may be removed, or sutured closed and left in the abdomen. An end colostomy is usually a permanent ostomy, resulting

from trauma, cancer or another pathological condition, although it may be reversible depending on the quality of the bowel down-stream.

**Double-barrel colostomy** – This was an old fashioned procedure and involved the creation of two separate stomas on the abdominal wall. This procedure is very rarely carried out these days and is in effect the fore runner of the loop colostomy.

**Loop colostomy** – This colostomy is created by bringing a loop of bowel through an incision in the abdominal wall. The loop is held in place outside the abdomen by a plastic rod slipped beneath it. An incision is made in the bowel to allow the passage of waste through the loop colostomy. The supporting rod is removed approximately 7-10 days after surgery, when healing has occurred that will prevent the loop of bowel from retracting into the abdomen. A loop colostomy is most often performed for creation of a temporary stoma to divert waste away from an area of intestine that has been blocked or ruptured. This is reversible.

**Hartmann's procedure** – This operation is usually performed in an emergency when it would be unsafe to reconnect (anastomose) the bowel and leads to the formation of an end colostomy. This is potentially reversible at a later date, to reconnect the bowel.

**Total Colectomy** – This is removal of the entire large bowel (colon)

**Hemicolectomy** – This refers to the removal of about half of large bowel (colon) and may be therefore right of left.

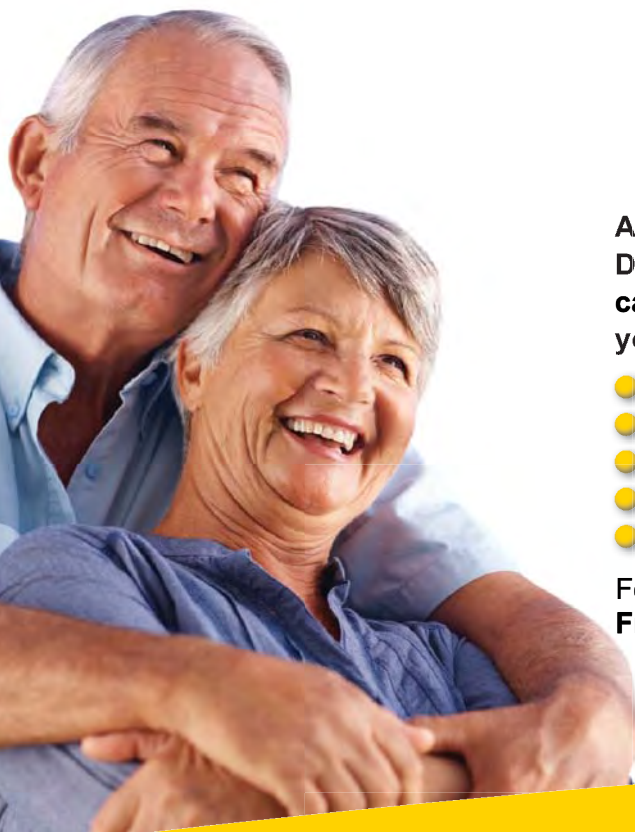
**Anterior resection** – This is a removal of part or all of the rectum, which is the lowest part of the large bowel and the part immediately above the anus. Removal of the upper part is called a High Anterior resection, the entire rectum removed is called a Low Anterior Resection and is usually accompanied by the formation of a temporary loop ileostomy.

**Abdominoperineal excision** – This involves the removal of the rectum and the anus, which is the outlet

control mechanism. Removal of the anus means that continence is no longer possible and an end colostomy is needed.

**If you have come across a medical term associated with your ongoing treatment or past care that you think requires further explanation please do get in touch...**

**write to:**  
**The Editor**  
**Colostomy Association**  
2 London Court  
East Street Reading  
Berkshire RG1 4QL  
or  
**telephone:**  
**0118 939 1537**  
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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](mailto:ursulanaish620@btinternet.com)**



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** our 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 hours a day...every day!
- **Over ninety contact volunteers covering 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** and keeps 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](http://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.

<b>Note:</b> Please ensure that we have your correct details: full name, address and postal code thank you	<b>My Details:</b> Title: _____ Name: _____ Surname: _____
	Address: _____
	Postcode: _____
	Telephone number: _____ Email: _____
	<b>Optional Information:</b> 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**

To the Manager: (Bank or Building Society) \_\_\_\_\_

Bank Address: \_\_\_\_\_ Postcode: \_\_\_\_\_

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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** Sort code: **60-17-21**

the sum of £ \_\_\_\_\_ amount in words: \_\_\_\_\_

**Date of first payment:** \_\_\_\_\_ and thereafter on the same day every month/quarter/year)\*

(\*Delete as appropriate) until further notice. (Please cancel any previous standing order in favour of this beneficiary )

Name: (IN CAPITALS) \_\_\_\_\_

**Signature:** \_\_\_\_\_ **Date:** / / 2012

**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 £ \_\_\_\_\_

I enclose a **cheque/postal order form** made **payable** to the **C.A. Ltd - Thank you!** **Yes, I require a receipt** (Please tick.)

*giftaid it* **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:** / / 2012



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*ami*  
COLLECTION

One young lady came along to a meeting...we didn't see her again...until she wrote some time later saying that the two hours she had spent with us had changed her life, younger by many years and new to living with a stoma she had thought her life was over until she met members of the group who had lived with their stomas for many years who continued to lead a full and enjoyable life. She returned to work and started living again!

## Jackie Dudley writes on....

**Starting up a support group...‘it never ceases to amaze me how many new patients are never told about this kind of help and support...’**

The hospital stoma care nurse asked me if I would start up a support group to help new patients receiving stomas. I was delighted to be asked because when I received my colostomy – it was over a year later before I actually met other people like me – living with a stoma. In fact it was a support group experience – a coffee morning as I remember – that really helped me, I'll never forget it! Over the few hours that I was there, I learned so much! More than I could ever have dreamed possible (certainly much more than the past 12 months on my own) from real people with real life experiences of living with a stoma. It was the practical suggestions that made an impact on me. Simple answers to questions like, 'How do you hold up your clothes while changing your pouch?' A simple task you might think, well not exactly and I am sure many of you reading this will know just what I mean! A great tip came from one member in the group – use a peg to clip the excess material away from your pouch! Other ideas were also discussed and I came away with a great deal of knowledge wishing I had met people with a stoma much earlier.

So on Monday afternoon the 4th July 2005 (Independence Day!) – I sat in the hall of the local community centre waiting to see who would turn up to attend the first advertised meeting of the East Berkshire Ostomy Club.

Previous to that day I had approached the Trustees of my local Community Centre to find out if I could have the hall they agreed and gave it to me – rent free – on Monday afternoons between 2.00-4.00pm. I had decided to hold meetings every Monday afternoon, as the nurses were concerned about new patients missing the meetings that had taken place before they were discharged



Members of the East Berkshire Ostomy Club

from hospital. Holding a meeting every week was a huge commitment but I agreed with the stoma care nurses that support should be offered on a regular basis so no one would have to wait too long to meet others who knew how they felt.

I put up posters in the local supermarkets and the freebie newspapers. Bracknell Forest Voluntary Service also helped by putting the notice in libraries and community centres. The posters were very simple A4 sheets stating where and when the meeting would take place. I tried various 'pictures' to attract the eye to the information – cups and saucers, a tea party, stick men.

The meeting was advertised to start at 2.00pm and as the clock struck, my first attendee walked through the door. We put the kettle on, made tea and sat and talked. As we were the only two people there we were able

to have a long discussion about 'living with a stoma'. I came away from that meeting knowing that I had done the right thing in trying to start up a support group. The next week more people came turned up. Over the years the group has grown and we are now averaging between 20-30 people. We have a mixed group of people – urostomates, ileostomates and colostomates, partners and family members all are welcome and individually they each bring something different – great ideas, empathy and support for one another.

Sometimes I get a little despondent when I realise that new members come along because they have 'heard' about the group usually from a member, which is great but I would really appreciate signposting from those involved in patients medical care especially from GPs, stoma care nurses and surgeries. It is always an added incentive for Ostomates to attend a meeting when a stoma care

nurse is present or is kind enough to help run the group. The nurses are the first people patients turn to when they have a problem with their stoma and it would be great if more could get involved with patient support groups. A medical professional attending one of the Colostomy Association's Patient Open Days made an interesting observation – stating that the questions patients asked at the Open Day were very different to the ones they asked in clinic.

When I listen to the chatter at my support group I realise how many problems are resolved through discussion. If the group helps just one person then it has achieved what it set out to do. I remember one young lady who came along to a meeting and we didn't see her again. She wrote some time later saying that the two hours she had spent with us had changed her life, younger by many years and new to living with a stoma she had thought her life was over until she met members of the group who had lived with their stomas for many years who continued to lead a full and enjoyable life. She returned to work and started living again!

I have read about and admired those people who have started up support

groups that list large numbers of attendees. Somehow mine has never got really big. Maybe I started off wrong? I don't have a committee to help with the running of the group but I do have willing helpers, who make the tea and set up the room. There is no committee as such, but what I have is a lovely social gathering each Monday afternoon. Those who come along can relax, chat, buy books (we run a book club at 20p per book) and pick up manufacturers samples, Tidings magazines and Colostomy Association literature. Activities include a quiz every second Monday in the month and a raffle on the last Monday of the month, manufacturers' representatives visit to show their products and we invite speakers on various subjects. Most of all – we welcome everyone who wants to come along and join us!

At the moment we are raising funds for Breakaway as we want to sponsor a child to attend a weekend away – we have Wendy Hetherington, a Trustee of Breakaway coming along on the 30th July to tell us more and to accept a cheque on their behalf.

So – if you have ever hesitated about starting up a support group – and have been twiddling those thumbs

and wondering what to do with yourself setting up a support group might be just the answer! It doesn't matter if you hold your meetings in your own front room, in a hall or in a large arena – the whole point of holding these get togethers is to make a difference. Knowing that you care and have helped those who need support is enough.

Rest assured you would receive plenty of support from the Colostomy Association to help you set up a support group. The CA can help with leaflets, posters and a mail shot to those Colostomy Association members in your area telling them about a new support group. It never ceases to amaze me how many new patients are never told about this kind of help and support. The Colostomy Association has a special page in Tidings, listing support groups throughout the UK. Let's make sure yours is added very soon.

**Jackie Dudley**  
CA Trustee and Volunteer

*"39 years of sore skin... completely gone!"*

Jenny, ostomate, UK

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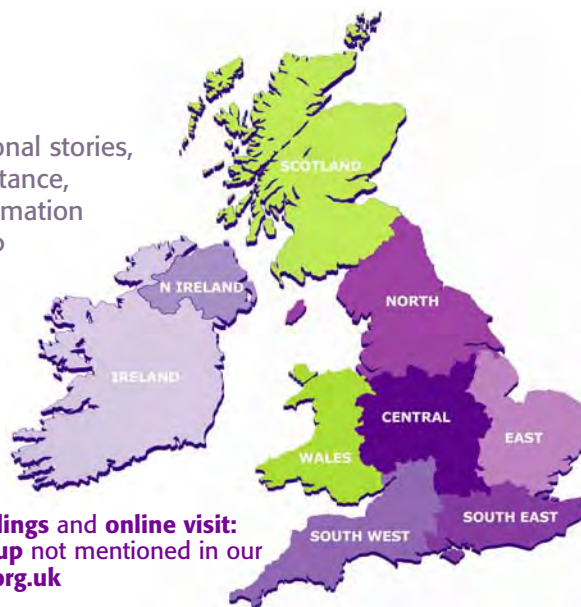
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**Support Groups** are places where people can share personal stories, express emotions, and be heard in an atmosphere of acceptance, understanding, and encouragement. Participants share information and resources. By helping others, people in a support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

## Stoma support groups in your region...



Information about **support groups** is regularly updated both in **Tidings** and **online visit: [www.colostomyassociation.org.uk](http://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](mailto: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'Donnell  
01236 436479 or Charlie  
Sutherland 01698 822075

#### Ayrshire:

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

#### Fife:

Fife Ostomy Support Group  
Contact: Ishbel Barr 01592  
772200

### England - North

#### Cheshire:

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

#### Cleveland:

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

#### County Durham:

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  
Trafford Bowel Care  
Contact: Jackie Carey  
(Secretary) 0161 7489 659  
Doreen 0161 9627 818 John  
0161 7484 655

#### Merseyside:

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

#### Northumberland:

Northumberland Cancer  
Support  
Contact: Mary Miller 01661  
842029

#### Tyneside:

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

#### Yorkshire:

Airedale Stoma Support  
Contact: Jenny Shaw 01535  
652516  
or Sue Hall 01535 210483

Behind You (Calderdale &  
Huddersfield Bowel Cancer  
Support Group)  
Contact: Stoma Care Nurse  
01484 355062  
CROPS (Colo-rectal ostomy &  
internal pouch support)  
Contact: Gloria 0114 2879503  
Dewsbury & District Ostomy  
Contact: Janet/Eileen 0844  
8118110  
Rotherham Ostomates Caring  
Support  
Contact: Karen 0788 0575758  
Scarborough Stoma Support  
Contact: Sister Jean Campbell  
01723 342388 Amanda Rowe  
01723 342446

The Hull and East Riding  
Colostomy Support Group  
Contact: Pete Smith 07989  
565335 and Pete Rennard  
01482 793966

#### Isle of Man:

Stoma Support Group  
Contact: Carole Cringle 01624  
650212

### England - Central

#### Buckinghamshire:

Milton Keynes Stoma  
Association  
Contact: Mrs Joanne Dixon  
01908 318262

#### Leicestershire:

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

#### Nottinghamshire:

Nottingham Colostomy,  
Ileostomy & Urostomy Support  
Group  
Contact: Rosemary Brierley  
0115 982 6691  
Nottingham Stoma Support  
Contact: Mrs B Heath 0115 966  
3996  
North Notts Stoma Support  
Group  
(Sutton-in-Ashfield)

Contact: Tore and Nicky  
Norman 01773 715460

#### Shropshire:

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

#### Staffordshire:

Outlook  
Contact: Ernie Hulme 01782  
324441 Joan 01782 710828

#### Worcestershire:

Kidderminster & District  
Colossus Support Group  
Contact: Brendon Drew 01299  
400843

#### West Midlands:

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

### England - East

#### Bedfordshire:

Saturday Social Club  
Contact: Karen Richards  
01234 792278

#### Cambridgeshire:

Ostomistics  
Contact: Heather Connor  
01733 768332 Mob:  
07757167422

#### Essex:

Connect  
Contact: Lin Hart 01279  
505273  
M.E.S.S (Mid Essex Stoma  
Support)  
Contact: Paul Foulger 01245  
224374 Jeanette Johnson  
01376 511862  
N.E.S.S (North Essex Stoma  
Support)  
Contact: Mr 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:

Solent Ostomates Support Group  
Contact: Carole Summer 07527 707069

Wessex Urology Support Group  
Contact: David Morris 02392 361048

#### Isle of Wight:

Optimistics  
Contact: Stoma Nurse 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 Group  
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:

East Surrey Stoma Support  
Contact: Pat Woodford 01883 344820  
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:

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: CA for details 0800 328 4257

##### Wiltshire:

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

#### Wales


Blaenau Gwent Self Help  
Contact: Celia McKelvie 01873 852672  
Bridgend Ostomy Patients Support Group  
Contact: Jackie Walker 07843 988 432  
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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# RESPONDER

## HOME DELIVERY SERVICE

PROVIDING A FAST, TRULY  
PERSONAL AND DISCREET  
SERVICE SINCE 1991

The UK's leading independent  
supplier of Prescription Appliances



- ✓ FREE DELIVERY
- ✓ FREE DISABLED TOILET KEY
- ✓ QUALITY ASSURED
- ✓ IMPARTIAL ADVICE
- ✓ AWARD WINNING CUSTOMER CARE
- ✓ FREE GIFT

Try the **RESPONDER**  
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Call **0800 220 300**

[www.ostomart.co.uk](http://www.ostomart.co.uk)

**You'll be glad you did!**

Our high levels of customer service are recognised  
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## Why choose the **RESPONDER** service?

- > Award-winning personalised service
- > Free home delivery of all your stoma or continence prescription requirements with all manufacturers' products stocked and supplied
- > Electronic Prescription Service (EPS) – making ordering quick, easy and hassle free
- > Online ordering facility
- > Free Disabled Toilet Key
- > As we do not manufacture pouches, we can offer impartial product advice and a complimentary sampling service
- > Quick, discreet and reliable overnight delivery
- > Free gift and MRSA resistant flannel with first order
- > Deliveries can be made to any chosen address and left without a signature if required
- > Open on Saturdays
- > Ultrasonic, computerised cutting of all appliances to your exact stoma size/shape
- > Free dry or wet wipes or disposable bed & chair pads with each order
- > Free scented disposal bags
- > ISO Quality Assured Service
- > BTEC qualified stoma & continence customer support staff
- > Access to Stoma Care Nurses for unbiased product advice & support
- > Prescription collection from your GP if required
- > We are a proactive supporter of stoma charities within the UK

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