Autumn 2011 | Issue 23

colostomy association

Tidings

Dedicated to Colostomates their Families and their Carers

Cover story
Mary steps up... to the challenge

Pathways to a colostomy
Josephine's story

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21st DEC

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SCOTLAND
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welcome to AUTUMN

Did you know...

Currently in the **UK Parliament** there is an **Early Day Motion 1650 - Paper Towels in Retailers' Public Toilets.** The EDM was tabled on 23rd March this year by Bill Esterson MP.

Early day motions (EDMs) are tabled by MPs to publicise a particular event or cause, and to gather support among MPs for that event or cause. MPs demonstrate their support for an EDM by signing the motion.

The following is an extract...

The findings of Redway and Fawdar at the European Tissue Symposium in 2009 demonstrates the ineffectiveness of warm air dryers and jet air dryers in reducing levels of bacteria on the skin; further notes that both methods of hand drying produce a mean increase in bacteria and that, for users of colostomy bags for whom sanitation is a paramount concern, the bacteria present through blow air drying methods are particularly hazardous when changing colostomy bags; welcomes the fact that certain major retailers are installing paper towels in all disabled toilet facilities; and urges the Government to make the installation of paper towels in a disabled toilet facilities a legal requirement to safeguard the health and safety of colostomy bag users.

Some 23 MPs have signed in support of EDM 1650 those amongst them are:-

Rosie Cooper MP
Glenda Jackson MP
John McCrea Mp
Dr William Roy MP

To learn more visit:
www.parliament.uk/edm/print/2010-12/1650

Only a YEAR to go to World Ostomy Day! Saturday 6th October 2012...
If you have any fundraising ideas or suggestions on how CA can celebrate **World Ostomy Day...**contact the Editor via email:
editor@colostomyassociation.org.uk

Welcome to the autumn issue of Tidings...

As the leaves turn I am certain that most of you will have managed a holiday or some sort of break over the summer months. It's so important to get away and gain some perspective on life!

Travelling can pose problems for the ostomate. I know that for some of you just managing to go through the front door or pop down to the shops can be a huge challenge but small steps can lead to big strides! Certainly some of the real lives stories in Tidings show big strides are possible. However, we must never forget everyone's journey is different – the dilemmas and problems overcome by one person – may be different for another – 'living with a colostomy'.

The Colostomy Association is here to help you...did you know that the Association offers a totally confidential freephone helpline service 365 days a year! The best thing about it is, it's manned by people just like you, who are 'living day-to-day with a colostomy'. They too have battled with, managed, come to accept and in certain situations welcomed their stoma. I have met some of these amazing individuals who are – fully trained CA volunteers – passionate, caring, dedicated and resilient – they are there to help and support you whenever you need it. Details can be found on Page 6 – 'How to get in touch'.

Part of this charity's remit is to reach out to colostomates who may need support and reassurance but are unaware of the Colostomy Association. How can we find them? It's a challenge, I agree! Late in life my mum received a colostomy which misbehaved on many occasions, if only she and I had known about the Colostomy Association it would have made huge a difference to both of us! Therefore I would like to call on everyone who reads Tidings – whatever your walk of life – to speak out about 'living with a colostomy' and spread the word that 'the CA provides support, reassurance and help to those 'living with a colostomy, their families and carers'. If we find just one person who we can help then it's a job well done...if we find others...even better! Being part of the Colostomy Association is like having an extended network of family and friends who you can call on whenever you need to, they will always listen and understand!

Thank you to everyone who wrote in or emailed, especially those of you who picked up on the article 'travelling through airports'...you will find a follow up on page 42. This issue of Tidings contains a lively mix of articles and stories; I am especially pleased that the surgeon's story I mentioned in last issue is now included. We also have a feature on Parastomal Hernias and I would like to invite your comments, so please send in your thoughts and experiences. There is also another excellent article from Sophie Medlin BSc RD Colorectal and Nutrition Support Specialist Dietitian at Torbay Hospital who writes this time on high output stomas. Rosemary Brierley, Associate-Editor, gives us her personal perspective on Disposal. I am looking forward to reporting on the forthcoming Colostomy Association Open Day in Leeds, this October in the next issue of Tidings so until then – take care and keep in touch!

Jane

Jane Wood
Editor

Email:
editor@colostomyassociation.org.uk

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

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Contact CA office on 0118 939 1537 to get yours today

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About...the Colostomy Association

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

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

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

By telephone:
General Enquires: 0118 939 1537

Stoma care queries only:
Freephone Helpline: 0800 328 4257

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

Find us on Facebook:

Find us on Facebook

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

Don't delay... Donate Online today!

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

1

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

JustGiving

2

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

Tidings is YOUR Magazine...

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

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

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

Feedback... We are always trying to improve your Magazine and welcome your feedback. Enjoy this edition 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 300 ppi in RGB mode and scan original @100%.**

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

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How to contact the Editor

By letter write to:

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Berkshire RG1 4QL

By telephone via CA Office:
0118 939 1537

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

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

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30 Wipes

News...from the office

The Colostomy Association recognises the work of Iris Clifford – volunteer and passionate supporter of the charity who sadly passed on earlier this year...

Friend and fellow CA volunteer Judy Colston writes...

It is with much sadness that I write to tell you about Iris Clifford who passed away on 4th May 2011 aged 74.
Iris was one of our valued volunteers and I'm sure if any of you ever rang and spoke to her on the telephone helpline, you will remember hearing her lovely Irish accent.

I remember very well my first meeting with Iris in 2004 when I was asked by the stoma care nurse at the Lister Hospital in Stevenage, Hertfordshire to visit her, following her surgery.

It certainly didn't take her long, once she recovered, to want to become a volunteer herself and we attended training sessions together. She was passionate about the Colostomy Association and loved attending Open Days listening and talking to people and taking her turn on the Freephone Helpline.

Iris lived in the village of Weston in Hertfordshire which she enjoyed. She helped with the church flowers and other activities including showing other members of the village how to make Christmas decorations and arrangements. She was a member of the village Luncheon Club and took her turn on the serving rota.
Iris was a widow with two married daughters and four grandchildren.
She will be missed so much by us all.

New to CA!
Telephone donations...

Donations can now be taken securely by telephone via RBS WorldPay simply call the Colostomy Association office during working hours to donate.
Your donation will make a difference!

People person...Maureen Kelly-Smith bows out of SecuriCare Medical after giving a stunning performance!

Maureen is a special lady with a big heart and a big hug! She is someone who really cares – a people person! In fact it was this aspect of Maureen's personality that inspired her to start the Careline – a place where ostomates could find answers to questions, have access to samples and all makes and brands of products. Moving on in SecuriCare Maureen took on a Public Relations role, and hasn't looked back since! She has organised and managed countless open days and patient events, and has 14 fashion shows to her credit including our own at Reading University back in 2008 where CA Chairman, Monty Taylor and other CA volunteers modelled some amazing outfits!

A passionate supporter of the Colostomy Association, Maureen has done allsorts from putting up product sample boards in the office, to raising awareness at the Royal College of Surgeons, sitting in on the steering group for the last CA Open Day and kindly organising sponsorship which covered the cost of the venue, and visiting Manchester Airport to learn more about body scanners. Back in 2004/05 Maureen also sought Royal Patronage for the Colostomy Association which resulted in two invitations to Buckingham Palace!

So, what will Maureen get up to next well that remains to be seen – she will spend more time with her family and lovely husband Derek – but has intimated that she may go back to her roots – nursing – Maureen worked at Queen Charlotte's Hospital for nine years prior to SecuriCare, helping to bring babies into the world and loved it! Recently her step-daughter professed an interest in becoming a 'Doula' (an experienced woman who offers emotional and practical support to a woman and couple before, during and after childbirth), fascinated by the term Maureen looked it up on the Internet and was hooked!

Maureen would like to express her thanks via Tidings to SecuriCare Medical for giving her the opportunity to make her job her own! She would also like to thank and remember all the wonderful people she has met along the way. The CA would like to say a BIG thank you to Maureen – for just being you!

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

Donations
When sending your donation/s **please mark your letter/cheque** with **Tidings Issue 23....**
Thank you!

Coffee consultant... Richard shows his hand to raise funds!

Forty year old Richard is keen to raise funds for the Colostomy Association. In an intimate interview he explains just why it's so important to him...

My illness didn't really come to light until I had a serious perforation of my bowel due to Irritable Bowel Syndrome (IBS). Not so long ago I found myself in A&E! I received four operations – to drain all the mucus from body – that went in after my lower colon burst! Three and half weeks later I left hospital with a colostomy and went to live with my parents for a short time. Whilst I was recovering I must have tried every bag out there but the Salts Healthcare standard bag came out tops for me! Salts were so helpful.

But the biggest support – specifically emotional – came from the Colostomy Association. My stoma care nurse referred me to the Association and I am so grateful, the help I received was wonderful. "To be honest words are not enough, it's like the CA stopped me from entering the dark tunnel of depression that I assumed went with 'living with a bag'. Your volunteers' especially Ernie Hulme and stoma care nurse Amanda Gunning truly rescued me from deep despair."

So, I felt compelled to do something to help the Association to continue supporting people like me! The idea of a tattoo flashed across my mind! A colostomy is hidden from the world not only by clothing but also by fear; I hope by placing the tattoo on my hand – a highly visible place – people will see I wear a bag 24/7! My hope is to raise as much money as possible for the charity and at the same time highlight bowel disease!

About Richard...
Originally from Edinburgh but now living in the North East for the last 18 years, Coffee consultant, Richard opens, fixes and runs coffee houses and cafes. His 17 year old daughter who is his world keeps him motivated and positive! To Richard being a dad is very high on his agenda. Playing the bagpipes is one of Richard's hobbies he has done so since he was 10. Other interests are art and design, fashion and of course tattoos! Richard's family still live in Scotland, his parents retired to Dunoon and his sister lives in Edinburgh with her son.

If Richard's story has inspired you to fundraise, write in and let us know about your activities or if you would like to make a donation to the CA please see Page 55.

500 Club - June Draw

Mrs B Willis	£312.00
Mr D Ogden	£156.00
Mr R Taylor	£ 62.40
Anon	£ 62.40
Mrs S J Oldman	£ 62.40
Anon	£ 31.20
Mrs M Smith	£ 31.20
Mr R A Thornes	£ 31.20
Mrs C Boxall	£ 15.60
Mrs J Holness	£ 15.60
Mrs SE Garrett	£ 15.60

Probus Club of Sherwood Forest nominates the Colostomy Association as charity of the year!

Thank you to The Ladies Probus Club of Sherwood Forest for their generous donation of £607.96. Elspeth Lindsey whose husband, Phil, has had a colostomy for fifteen years, nominated the Colostomy Association as the charity for her year as president (2010-2011).

The CA is very grateful to members of the Probus Club for their hard work to raise these funds, in particular their very successful annual coffee morning held at Edwinstowe Village Hall on Saturday 12th March.

About...Probus clubs
Probus clubs comprise the fastest-growing Rotary club-sponsored organisation today, attracting a burgeoning population of retired and semi-retired business and professional people.If you would like to learn more about the work of Probus Clubs... visit: www.probus.org

Your spare change may seem like a small amount, but when added with others', it can make a HUGE difference...

A donation box is a great way of raising funds...

remember the saying - "Look after the pennies and the pounds will take care of themselves."

- So, why not keep a box at home and encourage everyone to pop in their loose change.
- Take a box along to your local support group.
- Or, ask if you can place one in reception or in the canteen.

Note: Do offer something in return - place a small brochure, nearby with information about the CA, or some CA sweets next to your donation box as a 'thank you' to donors.

This thoughtful gesture will lend validity to our cause and give the Association some free publicity. It can also help spread the word about the need for donations.

If you would like a donation box just call or email the CA and we will post one out to you.

Happy Fundraising!

Dear Friends...

On May 20th I celebrated my 80th Birthday. My family had arranged a grand tea party in the garden. It was a beautiful sunny day enjoyed by everyone. On my invitation cards I stated no presents thank you. I have all I need but donations to the Colostomy Association would be very welcome. I am very pleased to send the sum of £100.

Yours
M I

Thank you everyone for your kind donations

Dear Colostomy Association

Please accept a donation of £40 to your charity. We recently celebrated our ruby wedding anniversary and one of our gifts was £40 to a charity of our choice. As a colostomate I have chosen your charity to help you continue the valuable work you do.

Yours sincerely
M S

The Trafford Bowel Care Support Group...donated £200 as a thank you for our generous support!

Dear Tidings

Please find enclosed a donation of £120. This was raised from a get together we hold in our avenue, something we do every year, we decided the CA would benefit this year. I have found the Tidings magazine a huge source of information.

Yours Truly
CB

Dear Sir/Madam

I am enclosing a donation for £200 which is part of the proceeds from my annual coffee morning which I hold for bowel cancer. The remaining £100 I have given to Acorns for their work with children and cancer.

Kind regards
RG

Dear Friends

Please accept a donation of £40.00 from the Penny Black Club. The club is a collection of volunteers from the Royal Mail workforce, postmen, postwomen and managers, in Belfast who carry out excellent work for their sponsored charity, the NI Children's Hospice. The work they do is so impressive that their 'leader', a postman called Mal McGovern, was awarded the national Royal Mail Chairman's Award in 2010. This is the highest staff recognition award in Royal Mail. Mal has also received several community awards in Northern Ireland.

They are a fantastic bunch and I was surprised and touched that they actually give me (and the CA) some thought presenting the donation on my last day.

Best Regards
C K

Legacies...

Dr J R Collins	£ 500.00

Thank you

Did you know...

The Bournemouth Insurance Group (CATIP) provides travel Insurance for Ostomates

The Bournemouth Insurance Group (CATIP) provides a policy specifically designed for ostomates by an ostomate. With this scheme everyone wins - the Colostomy Association benefits by receiving a commission on every policy written and you win because the policy is bespoke - designed for your needs and highly competitive. We would like to say a huge thank you to everyone for continuing to support this initiative. So far this year the funds raised amount to £202.42.

For more information visit: www.colostomyassociation.org.uk or contact head office on 0118 939 1537.

Don't forget our Recycling project...

For a freepost envelope contact: www.recyclingappeal.com or Tel: 08451 30 20 10 quoting the Colostomy Association as your charity.

In Memory...

Mrs M I Clifford	£57.00
Mr D Pretty	£340.00
Mrs K Strohmeier	£170.00
Mr K Hill	£355.00

Thank you

Donations in lieu of flowers...

Making a donation in memory of a loved one is a special way to honour their life and passions. By arranging for donations in lieu of flowers your donation will not only go to supporting those 'living with a colostomy' today but will help to secure the future of the Colostomy Association.

We appreciate your kindness...

CharityFlowers.co.uk
Provided by Guernsey Flowers Ltd

Did you know...Charity Flowers donate 15% for every bouquet ordered. This year to date we have received £60.45. By choosing to purchase your flowers via the website www.charityflowers.co.uk you will be giving more than just beautiful flowers.

You will be helping the Colostomy Association, as 15% of the retail price of each order goes to the charity. Please quote 'COL' on all orders. Send for your FREE catalogue today or visit:www.charityflowers.co.uk or simply telephone 0870 5300600


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How I **stopped worrying** and **learned** to **love my stoma!**

It was my niece's birthday (May 9th 2001): the day I decided to go and see my GP to discuss the way my bowels had been behaving lately. He examined me then asked if I would mind if he called in a colleague. She was a new doctor and after having an examination of my bottom they both commented Ugh Ugh! No mention of cancer yet, it had to be proved by biopsy. They knew and I knew what it was but I walked home digesting the thought I was sixty-six and my mother had died of bowel cancer at sixty-six! Unnerving or what? My Mum did not speak about her symptoms until it was too late. I decided that whatever this "thing" was I would confront it and hopefully get rid of it.

I was given an appointment with a gastroenterologist very quickly. A biopsy was taken and when that proved cancerous I was given a counsellor who talked to me and my husband all about what would happen next. After that my feet did not touch the ground: MRI scanner, ultrasound on my liver, X-rays, blood tests and the dreaded barium enema. This was not as bad as I had expected and the staff in the clinic were very jolly. One month from diagnosis and almost every medical person in Nottingham had seen my bottom!

My family and friends were very supportive. My two sons were worried: No 1 son was positive and gave me a slap on the back saying 'You can do this, Mother dear.' No 2 son wept, but soon got over it.

Mid July I had an appointment to meet my surgeon who decided it would be a good idea for me to have radiotherapy for six days prior to my operation. So I proceeded to radiology every morning, stripped my bottom half, lay on my tummy and was zapped on the exact spot proved by X-rays etc. Very precise work and not painful. My last appointment was Saturday morning. This was the day the technicians cleaned their equipment, but they fitted me in at 7.30am before they started dismantling their machines. As I left all the staff showed me out and wished me good luck.

The next day I was admitted to ward E14 QMC. I was put in a private room with toilet and given my laxative and black tea. I spent the night mostly on the toilet purging my bowels. Early next morning I had a lovely warm bath and mentally photographed my tummy "before stoma"! Then my stoma nurse drew a ring on my tummy where my stoma was to be situated and I was wheeled down to the operating theatre wondering if I would survive!

Thanks to a very cheerful anaesthetist I was sent into dreamland and the next thing I knew my husband and both sons were leaning over me. I was not functioning then but much later I was really awake. I felt very stiff and had catheters, drains etc. all over. I was given a self administering morphine press button and drifted about until two nurses appeared and made me get out of bed to have a wash.

The morphine definitely worked and I was beginning to love it when it was taken away and I was put on Paracetamol. After two days my wound drain, then my bladder catheter and the drip were removed and I had to walk to the toilet and drink water.

I was wearing a drainable bag on my stoma and nothing happened until the middle of one night (as usual). I woke up to find a huge balloon on my tummy. I rang the bell and the nurse came and released the air from my bag and told me that my stoma was working!

After that my first cuppa tea – lovely! Then my surgeon came to see me and told me that when I produced a decent stool I could go home. This encouraged me to start eating and moving around the ward. It took a while during which a nice young nurse showed me my stoma and asked me to touch it. She showed me how to change my bag and gave me the confidence to do it myself.

Altogether I was in hospital for nine days. I came home with a large wound down my tummy held together with clips. My bottom had been sewn up and took a long while to heal. The district nurse came to remove my clips and organise my supply of colostomy bags. I slept a lot during the next few weeks. Then I received the news that all my cancer had been removed and I did not need any more treatment.

A month later I saw my GP for a check-up and he was very pleased to see me alive and well! Hospital check-ups went on for five years. First year was a liver scan, then a colonoscopy, a C.T. scan and so on. Since then my stoma and I have been to Australia – but that is another story. ■

Mavis Cordon


pelican
HOME
DELIVERY

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.**

Sensura® Mio offers life-changing 'Better Fit' solutions for colostomates...

Many people living with a stoma suffer anxiety and distress over the difficulties in fitting an ostomy appliance securely to their skin. The problems are usually worse for those with scarring, uneven skin surfaces, hernias and other 'body fit' issues. SenSura Mio® from Coloplast offers renewed hope for people who have endured physical and emotional discomfort, often over many years.

SenSura Mio® is a new colostomy appliance designed to fit individual body shapes. It features a pliable elastic adhesive that follows the body's contours and natural movements maintaining a secure fit thanks to its innovative design. SenSura Mio® not only improves body fit and reduces leakage but has the potential to change and improve the lives of people with an ostomy.

To learn more about SenSura Mio® and its innovative BodyFit™ Technology visit: www.coloplast.co.uk/products/ostomy/sensuramio

To order your FREE samples or to speak to our customer care team contact: 0800 220 622.

CUIWear are pleased to introduce a new range of Fulcionel bespoke hernia belts and girdles... Working closely with stoma care nurses and ostomates the staff at CUI are able to offer a fitting service for all shapes and sizes of hernias. The feedback regarding this service has been extremely positive as it is now possible to design and supply hernia support for individual requirements. The products are manufactured by CUI at their premises in Leicester.

For more information about our products contact us on: Freephone 0800 279 2050 (Freephone opening hours are Monday to Friday 9am to 5pm (excluding Bank Holidays).

Peak Medical is pleased to announce the launch of their new website...

You can now visit our new website which features our extensive range of ostomy appliances and accessories. Not only are you able to see what the products look like and read about their benefits to you but you are also able to order FREE samples online.

Simply visit www.peakmedical.co.uk to view our extensive range of ostomy products that are available to order through your delivery company or your usual supplier who will be able to supply any of Peak Medical's products.

OstoMART the leading independent ostomy supplier with 20 years in the business...launches new website www.ostomart.co.uk

The new site is designed to provide detailed information about stoma care products and services. You will find stoma care ancillary products, specifically made for ostomates – barrier creams, adhesive removers, odour neutralisers, security tapes to support garments, high-waisted underwear, stoma shields and made-to-fit pouch covers – request free samples online or via our freephone number: 0800 220300.

Need support? Our site provides links to the Colostomy Association, IA (The Ileostomy and Internal Pouch Support Group), Urostomy Association, and many others, and if you're looking for an open day near you where you can go and talk to other stomamates and specialists then take a look at our dedicated section. If you are looking for answers our Frequently Asked Questions section may help.

Our Home Delivery Service – offers unbiased product advice with product choice available from ALL manufacturers plus a free sampling service. If your pouches or flanges require cutting then our revolutionary Computerised Cutting Machine will ensure you have the best, most accurate and hygienic cut available.

To take a look at our new website visit: www.ostomart.co.uk or for more information about our products or services call Freephone: 0800 220300 or email: enquiries@ostomart.co.uk our friendly customer advisors are waiting to hear from you.

Apology from the Editor: A printing error occurred within the Appeel® product advert in the summer issue of Tidings – whereby the text line beneath the product image became corrupted leaving the word 'sting' isolated - it should be stated that this may have been misleading to readers' and customers of this product – therefore we apologise unreservedly to CliniMed Ltd and state the following...'Appeel® is a silicone based, no sting medical adhesive remover that removes stoma pouches easily and gently'.


CliniMed®
Essentials
Handle with care
Appeel
No sting
Medical Adhesive Remover
REF 3500
Appeel
No sting
Medical Adhesive Remover
REF 3505
Appeel®
NO STING
Medical adhesive remover

Update on stoma care products and services

From Pelican Healthcare... Pelican Protect Plus Non Sting Barrier Film with added Vitamin E

Pelican Protect Plus provides the optimum in skin protection with the benefit of Vitamin E to nourish and moisturise the skin. Pelican Protect Plus will safeguard the skin against adhesives, solid and liquid waste and enzymes. Pelican Protect Plus is supplied in a single sachet for discretion and convenience.

Pelican Support Stoma Waistband...

Pelican Healthcare is delighted to introduce the Pelican Support Stoma Waistband, a seamless unisex support garment in a soft and breathable fabric providing the ultimate in comfort, confidence and discretion. Pelican Support provides lighter support for small hernias, and is ideal for use during physical activities to provide extra security, support and confidence. Pelican Support provides a smoother body shape and is ideal for swimming and intimacy. Pelican Support is available in 3 sizes, and there is a choice of white or beige to suit all preferences.

For further information please call the Freephone Sample Helpline on: 0800 052 7471, visit: www.pelicanhealthcare.co.uk or e-mail: contactus@pelicanhealthcare.co.uk

SecuriCare

It's Official: SecuriCare delivers on what it promises!

Predictability and consistency are probably things you really value about your Home Delivery Service. These qualities "don't just happen", they're the result of planning and procedures that have to be successfully executed time after time to help ensure you receive what you need, when you need it. When a company believes it's got these things right, it can write up its processes into a Quality Management System and ask an independent, outside body to come and audit it.

We are delighted to report that after recent audits by Lloyds Register Quality Assurance, SecuriCare (Medical) Ltd has been approved to the ISO 9001:2008 Quality Management System.

Commercial Director Neil Freeman welcomes the accreditation, "which demonstrates that we as a business are committed to ensuring our processes and procedures conform to the exacting International Standards required, are commercially sound, and support our objective of enhancing customers' satisfaction.

Regular re-assessment against the international standards ensures that we don't rest on our laurels, and that we look to identify and implement continuous improvement initiatives wherever possible.

This is a significant business award and we are all proud of the achievement."

So you can rest assured that we'll always be working to keep our promises.

For more information about SecuriCare's services please call 0800 585125 or visit www.securicaremedical.co.uk.

World Assist Alliance... Fittleworth helps the travelling ostomate...

Fittleworth is the founding member of the World Assist Alliance – an international network of delivery companies just like ourselves. All organisations are dedicated to the delivery of stoma and continence appliances to the customer.

Each member has signed up to a promise, that should you have any problems with your products while in their country, they will help you out with emergency supplies of appliances and in most locations, specialist nursing advice if required. World Assist Alliance is currently available in the following countries, Australia, Austria, Belgium, France, Holland, New Zealand, Portugal, Spain, Switzerland and U.S.A.

The World Assist Alliance service is free for the supply of goods in emergencies. There is no need for a prescription and you do not need to claim on your insurance or complete any forms or paperwork.

Who is eligible?

Fittleworth customers who have had three or more prescriptions dispensed in the previous 12 months.

What the World Assist Alliance offers to business or leisure travellers...

- Worry free travel to destinations both near and far
- Free emergency supply of stoma and continence products
- No fees, no charges, nothing to claim back
- Access to local, specialist nursing advice
- Local delivery, by local companies, within a 48 hour period
- No customs or shipping delays
- No complicated systems or foreign languages to struggle with

For more information visit: www.fittleworth.net/world-assist-alliance.html or contact us on: 0800 378 846 or 0800 783 7148

Mary steps up to take part in the Clipper 11-12 Round the World Yacht Race – but as the day of departure dawns – plans are scuppered...

My husband took part in Clipper 05-06 and now it's my turn to take on the challenge of a lifetime! I've wanted to do the race for five years.

Mary Le Coyte, colostomate and jewellery designer from Somerset was all signed up for Leg 1 sailing across the Atlantic Ocean from the UK to Rio de Janeiro...when on the day of departure things didn't go quite according to plan...Mary takes up the story.

Sunday dawned bright and sunny, although high cloud in the west indicated a change in the weather to come. I stood at the window of my hotel room and watched a yacht, maybe 38 or 40 feet, motoring down Southampton Water in anticipation of a good Sunday sail. Flags in the hotel car park were fluttering bravely as if to herald the start of the race. As I watched, a familiar figure emerged from the hotel opposite – my own skipper was leaving early for Ocean Village and the boat that would be home for the next year...Visit Finland.

The day quickly warmed up, and by ten o'clock crowds were beginning to fill Ocean Village, drinking coffee in the sun, or laying claim to the best vantage points on the rail overlooking the boats. Small groups talked intently and exchanged emotional farewells – people of all ages turned away from loved ones and strode off as sailors to their new family of skipper and crew.

On Visit Finland, an air of contained excitement prevailed as last bits of kit were stowed, and final preparations for start were made. Friends waved and called from the viewing area.

At midday, the teams filed, one by one, onto the stage to be introduced by Joff Bailey, Race Director, before they joined their boats for the Blessing of the Fleet and departure from the marina. It was a wonderful, exciting moment for every crew member, and it broke my heart to watch, and not be on stage with those I'd trained with, worked with, and planned this incredible voyage with.

Yes, that's right. You didn't get that last paragraph wrong. After planning and working for this day for two years, I remained a spectator at Race Start. I was going nowhere.

A week earlier, whilst living and working on the boat with other crew to ready her for departure, I had started having severe abdominal pain, which culminated in a mad dash to hospital in Exeter to see the surgical team who know me and my stoma. (I shall forever be grateful to the dear friend who drove me all the way there as fast as he could, and then turned round to drive back to Portsmouth.)

I had an incarcerated parastomal hernia, a condition which, if it happened at sea and could not be resolved, had the potential for grave consequences unless emergency surgery could be performed. Discussions followed with doctors, race managers, and insurance companies as my symptoms were monitored, and on Friday morning it became apparent that sailing across an ocean this week was simply not an option. I must wish skipper and crew 'bon voyage', tell them 'sail fast, stay safe' and walk away as they left on the great adventure.

All is not yet lost. Hernia surgery will follow, and then I am hopeful of finding a place on Leg 8 of Clipper 11-12, joining the team in New York next June to cross the Atlantic from west to east, stopping in Nova Scotia, Northern Ireland and Holland before sailing into Southampton on 22 July, almost a year after I should have sailed out!

In the meantime, I'm contemplating a little light dinghy sailing to improve my wind awareness - it's said that the big boats get the glory, but the small boats make the sailor!

For me, the horizon appears to have receded into the haze of distance, but it's still there. So am I, and I'm still planning to sail out towards it!

About parastomal hernias...
Most hernias have the potential to increase in size as time goes by. Stoma hernias are rarely painful, but can be uncomfortable and inconvenient. They may also make it difficult to attach a bag properly and sometimes their size may cause embarrassment and emotional stress. Although complications are rare, the intestine can sometimes become trapped or kinked within the hernia and become obstructed. Even more seriously the intestine may then lose its blood supply, know as strangulation. This is very painful and requires emergency surgery to untwist the intestine and prevent the strangulated part of the bowel from being irreversibly damaged. Regardless of inconvenience or pain, hernias are defects in the abdominal wall and should not be ignored simply because they might not hurt. If you have any concerns contact your GP or stoma care nurse who will be happy to advise you.

You can read more about Mary on the following pages...

"I feel normal again with Vitala™. It's so liberating!"

A diagnosis out of the blue with bowel cancer comes as a shock for anyone, no matter how strong-willed and defiant you are.

Mary Le Coyte concedes that the surgery, illness and black days that followed her diagnosis two years ago drove her to consider buying a big armchair and learning to knit. But the 57-year-old is no quitter and explains why, despite being an ostomate and a novice sailor, she set her sights on one of life's greatest challenges, a round the world yacht race!

"I was still recovering from stoma surgery and cancer," Mary starts. "I was at a party and heard myself saying that I thought my sailing days were over. I was shocked with my attitude. I thought: I've got to get a grip! I can't let this get the better of me." She promised right then she'd apply for the next Clipper Round the World Yacht Race.

"Before the cancer I was a normal, busy, energetic person. In the past I'd had some 'interesting' hobbies like skydiving and flying!" she explains. "The surgery to remove my rectum and anus left me with a permanent colostomy. I thought part of my life was over."

Leaving hospital she developed a severe skin reaction to the colostomy bags. She says: "I tried practically every bag made. It was so depressing and I was extremely sore."
"Cancer is a very scary diagnosis for anybody, plus you have the stoma to come to terms with," she explains. "I was very defiant and went in saying: I'm not going to let this get the better of me! It's easy to talk like that beforehand.
"A few weeks later when you're learning about your stoma, trying to get used to it and your skin is inflamed, you can't help but think: actually, I really don't like this!"

Gradually, with the support of her family, friends and the stoma nurses, things did start to look up. Mary enrolled on the 2011–12 Clipper Round the World Yacht Race, for the first 4,900 mile leg from the UK to Rio de Janeiro. She'll spend seven weeks on a stripped down 68-foot racing yacht.

Don't give up
While Mary may have more of a taste for adventure than many, she has sound advice for other ostomates, or people worried about facing surgery.

"Don't give up on the things that you want to do," she urges. "Don't ever think, as I started to: I can't do that anymore, because, you can. As a new ostomate, it takes a little time to get your confidence back, but you will. Do everything you can to continue with the sort of life that you want."

"With Vitala™ I don't feel as awkward. Vitala™ helps me regain control of my life in so many ways!"

A turning point
A turning point came for Mary one year ago when her stoma nurse told her about a completely new product, the Vitala™ Continence Control Device (CCD), from ConvaTec.

Mary was immediately interested. "I saw its low profile and thought: this is amazing. It is so different!" she says. The Vitala™ CCD is an innovative device for people with end colostomies. It clips onto the flange of the Natura® adhesive skin barrier, in the same way as the Natura® bag does, allowing seamless interchange between using Vitala™ CCD and a bag. Fortunately Mary's skin can tolerate ConvaTec products with Stomahesive® technology. Vitala™ CCD can be worn for up to 12 hours at a time, so it has given Mary back so much more control over her life.

Feeling normal again
Mary enthuses: "I can take the train to London for the day without worrying about bags or finding a toilet. It's so liberating!" The most important thing was that Mary quickly realised that she felt different when she was wearing Vitala™ CCD. "I'm starting to feel normal again," she says. "The psychological effect is phenomenal."

As for the race, when Mary's working on deck heaving sails around or on a 4-hour watch, wearing Vitala™ CCD will make life an awful lot easier. She'll be able to focus on her job instead of worrying about her stoma.

"There is always the fear that your stoma will suddenly do something unpleasant. A noise or violent bowel movement when it's extremely difficult to find somewhere to go and deal with it," she says. "For me, Vitala™ has taken away that fear completely."

Mary admits there were very black times during the first year, but says: "If I had known there was an alternative that worked in a completely different way, offering more freedom than bags, then I would've felt so much more positive."

Vitala™ CCD isn't suitable for every ostomate, with types of surgery, cancer treatments and medications to be considered. Stoma nurses are trained to determine which patients it may suit. It only took Mary a few days to get used to Vitala™ CCD, by working up the wear time gradually. She was determined that it would work for her because she saw so many benefits to her daily life and the sailing adventure ahead.

Mary explains: "You can use Vitala™ for 12 hours in 24. You can choose to use it for 12 hours and then put on a bag for the next 12. Or use it for 6 hours to do something active, swap to a bag for a few hours, and you still have 6 hours in hand for later on."

During her race training, Mary wore Vitala™ CCD for 4-hour watches, changing to a bag when she came off watch. She says: "Vitala™ gave me a lot of confidence. I felt so secure on deck and with only two tiny toilets behind a zip-up curtain, it made life easier for me."

Vitala™ CCD transforms ordinary life. Mary now feels comfortable in a swimsuit and is considering a beach holiday again. She admits: "The other wonderful thing about Vitala™ is that you get your sex life back. Intimate relations can become very difficult with a stoma. With Vitala™ I don't feel as awkward. Vitala™ helps me regain control of my life in so many ways!"

You can follow Mary's progress on the Clipper Round the World Yacht Race at: www.convatecstomacare.co.uk/living-with-a-stoma/heading-for-the-horizon

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

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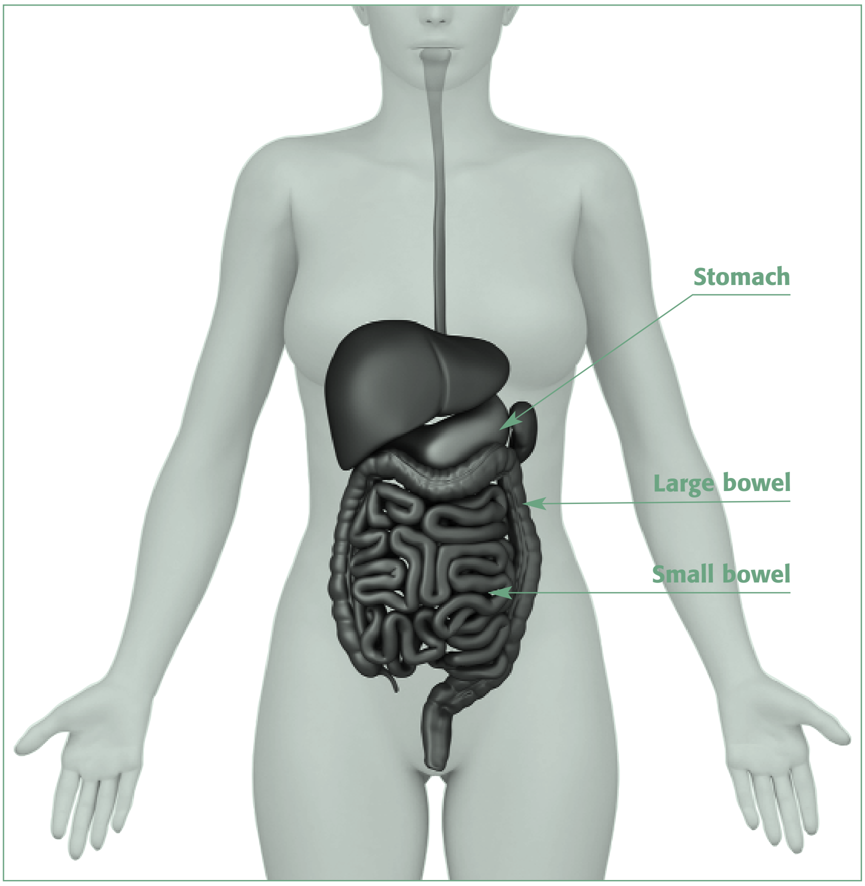
Sophie Medlin BSc RD Colorectal and Nutrition Support Specialist Dietitian at Torbay Hospital, South Devon Healthcare NHS Foundation Trust writes for Tidings on aspects of diet and your stoma...

Courtesy of South Devon Healthcare Foundation Trust

In another great article for Tidings - Sophie examines high output stomas which can often present management difficulties for patients and their healthcare team

Managing a high output stoma can be very difficult for patients and their healthcare team. High output stomas generally result from complex surgery and the expected volume of output will depend on how far along the small bowel the stoma has been formed. If the stoma is from high up in the small bowel it is likely that the output from it will be high and careful management is required. This is because there is only a short length of bowel available to absorb all the essential fluid, nutrition and salts. However, some patients with ileostomies in the very last part of the small bowel can also have a high output stoma. In general, people with colostomies should not have a high stoma output, please see the end of the article for further advice.

Sometimes a high output stoma is a temporary problem for instance, if it is very soon after surgery or you have a stomach bug. Also, some chemotherapy can cause a temporary high stoma output so if you are having chemotherapy after your surgery, discuss this with your oncologist or dietitian. Sometimes the raised output may last longer, but a few weeks or months after surgery your bowel may adapt and allow for adequate absorption. For some people, further surgery is required to improve their absorption and for others, a high output stoma is a permanent condition.



Many people find that the volume of stool they empty from their stoma will vary from day to day. This is normal and will depend on what you eat and drink, medications and many other factors. A 'High Output' is generally considered to be over 1000ml (1 litre) in 24 hours. If your stoma output remains significantly greater than this over an extended period of time you are at risk of becoming dehydrated, malnourished and depleted of essential salts such as sodium, magnesium and potassium and it is important that you seek help to manage your output.

If you're not sure if you have a high

output from your stoma (greater than 1000ml) you may find it useful to fill one of your usual bags with water and see what volume it holds. This way, when you empty your bag you will know roughly how much fluid you are losing. E.g. if your stoma bag holds 400ml and you empty it when it is half full (200ml) three times per day, you will have lost 600ml. Alternatively, your stoma nurse should be able to provide you with a jug which should only be used for measuring your stoma output and discarded once you have finished with it.

When, or if, you have a high stoma output, changes to your fluid and food intake will help to prevent dehydration and illness by preventing excessive loss of salt and fluid:

Fluids... The type and amount of fluid you drink will have a significant impact on your stoma output. All normal drinks will drag salts from your blood stream into your bowel. This salt will be lost in your bag along with the fluid. This means that the more you drink, the worse the situation becomes. When you have a high output stoma it is important that you have fluids which are easily absorbed and stop you from losing salts. Two examples of these drinks are St. Mark's solution, which was developed by the intestinal failure team at St. Mark's hospital in London, and Dioralyte which, should be double the

Foods to choose	Foods to avoid
Cereal foods White flour, white bread. White rice and pasta. Ground rice and semolina. Tapioca, sago and arrowroot. Custard powder and cornflour	**Cereal foods** Wholemeal or granary flours and breads. Softgrain and oatbread. Brown rice and wholewheat pasta. Wheatgerm.
Rice Krispies, cornflakes, Frosties, Sugar Puffs, Cocoa Pops, Ricicles.	Branflakes, wheatflakes, Allbran, Weetabix, Shredded Wheat, Muesli, Ready Brek and porridge.
Rich Tea, Marie and wafer biscuits, bourbon, custard cream, cream crackers, Ginger Nuts, Cornish wafers and 'Ritz' crackers. Plain cakes, plain scones and pastry made with white flour. Meringues.	Digestives, currant biscuits, flapjacks, cereal bars. Ryvita, Crackerwheat, wholemeal crackers and crispbread Wholemeal cakes, pastry and scones. Fruit cake and fruit scones.
Puddings Milk puddings. Jelly, mousse, smooth yogurts without 'bits.' Sponge pudding and custard Crumble topping made with white flour.	**Puddings** All other puddings made with wholemeal flour, fruit or nuts. Yogurts with fruit.
Vegetables Potato and sweet potato, (without skins) pumpkin, squash. Root vegetables: carrots, parsnip, swede, turnip, beetroot, celeriac. Lettuce, peeled cucumber, skinned & deseeded tomatoes. Cauliflower & broccoli florets (no stalks) Peeled marrow, aubergine & courgette. All vegetables must be well cooked. Remove skins and seeds where possible.	**Vegetables** Potato skins. Pulses – peas, beans (including baked beans) lentils Celery, sweetcorn, peppers Raw vegetables. Green leafy vegetables e.g. cabbage, artichokes, French or runner beans, mange tout. Radish, onions. Quorn
Fruit Fruit without pips, seeds and skins. Ripe banana. Canned fruit (not cocktail) Stewed fruit. Avocado.	**Fruit** Dried fruit. Fresh fruit with peel or seeds. Unripe banana. Strawberries, raspberries, rhubarb, pineapple, prunes.

normal strength (e.g. two sachets in 200ml)

These drinks should be used as your main drink and sipped throughout the day. You should aim for one litre per day. You may find that restricting your other fluids to 500-1000ml per day helps, discuss this with your dietitian or stoma nurse for further guidance.

The recipe for **St. Mark's solution** is as follows:

- 6 heaped 5ml teaspoons of glucose powder
- 1 level 5ml teaspoon of table salt
- Half a heaped teaspoon of sodium bicarbonate (bicarbonate of soda)
- Stir all ingredients into 1 litre of chilled water with a little squash to taste.

As a 'rescue remedy' when you are out and about and have had a high output or are thirsty, a packet of crisps and an isotonic sports drink taken together will help to rehydrate you and replace some of the lost salts. In general however, sports drinks do not contain enough salt to have the same benefits as St. Mark's Solution or double strength Dioralyte so will not be of benefit and can be very expensive.

Be cautious with alcohol as it can increase your stoma output, always stick to the recommended limits of 3-4 units per day for men and 2-3 for women with at least two alcohol free days per week.

Caffeine will also increase your stoma output as it makes the bowel work more quickly. Try decaffeinated drinks instead.

Avoid drinking half an hour before and half an hour after eating. This will prevent excessive mixing of the food with the fluid and can help you to absorb more nutrients.

Food... To help to replace lost salts it is helpful to add salt to your food. Try to add around a teaspoon per day to your food and add extra in your cooking. Starchy carbohydrates such as rice, pasta, potatoes, dishes made with maize or cornmeal, low fibre breakfast cereals, oats and chapattis will give you energy and help to thicken your stool. This will slow your bowel and help you to absorb more nutrients and fluid. It is important however to avoid high fibre foods as these will travel through your bowel more quickly. You should therefore always choose carbohydrate foods made with white flour and avoid the skin, peel and pips from fruit and vegetables. For examples please see the chart on page 21.

Some people find that the gelatine in jelly sweets and marshmallows is helpful to thicken their output. Try eating two to three marshmallows or jelly sweets before and after meals.

Medications... There are two key types of medication which can significantly reduce your stoma output. Antidiarrhoeal medications such as loperamide (Imodium) and codeine will slow the bowel down and allow more absorption of food and fluids thus thickening the stool.

Antisecretory medications such as Omeprazole and Lansoprazole are used to reduce the amount of gut juices your body produces. This will, in turn, reduce the volume of your stoma output.

If you are not on these medications and you think they may help you please discuss this with your stoma nurse, GP or consultant. Loperamide is used in much higher than normal doses in high output stomas, if you think you need to take more discuss this with your consultant or GP.

Colostomies... If you have a colostomy and the output is continually high and loose talk to your doctor. If you have had surgery on your small bowel it may be that bile, which is usually absorbed in the last part of your small bowel, is travelling into your large bowel and causing irritation and diarrhoea. If this is the problem is can be improved significantly with medication.

Your Questions Answered...

Q: *In the spring issue of Tidings it says drinking peppermint tea can help to reduce wind. I have wind that blows up my pouch, on and off, of an evening, after my tea, but at no other time of day. It only happens now and again, not daily.*

Please can you tell me, when I should drink the peppermint tea, at what time of day and how often. As I say the pouch only blows up after my evening meal, which is just a tea meal, not a cooked meal, I have my main meal at about one o'clock.
I have had my pouch for just over five years and am quite happy with everything else. I have just had my eighty-sixth birthday and am over the moon as, after having my scan and blood taken this year, I was given the all clear yesterday.

A: Firstly congratulations on getting the all clear. What wonderful news! What I would firstly suggest is that you make a note of what you have eaten and had to drink on the evenings you get the wind. It may be that you can identify the food that is causing the problem. If it isn't clear to you, ask to be referred to a dietitian who should be able to see a link.

If you would like to try peppermint tea try 1-2 cups after your meal and another before bed if the wind hasn't settled. This may not work for everyone but some find it useful.
I hope this helps.

Note: As always, this advice is very general and will not be suitable for everyone reading this article. If you are unsure please speak to your consultant, dietitian or stoma nurse.


QuietWear™
Material
virtually eliminates
embarrassing
pouch noise

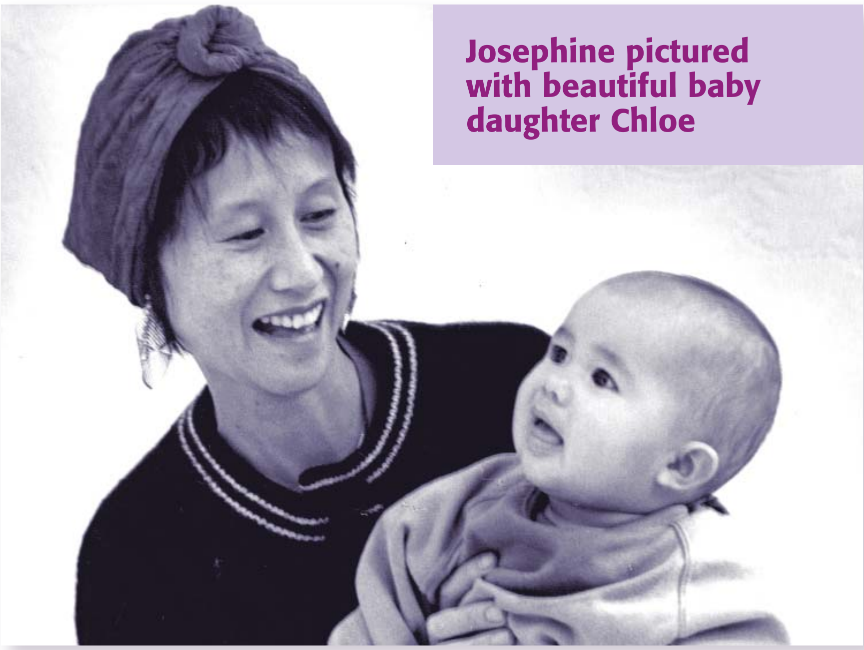
Pathways to a colostomy

A difficult labour...ended in an emergency caesarean...and the birth of a beautiful baby daughter...but a biopsy taken during labour revealed Josephine had bowel cancer...

All I could take in was that my daughter was healthy and, amazingly enough, completely unaffected by the cancer. I can remember responding that my father had colon cancer and that I must have inherited the condition; it was as though I needed a rational explanation.

Twenty-two years ago, at the age of forty-one, I went into hospital to give birth to my third child, in what I blithely imagined to be a speedy and trouble-free delivery. Apart from a rather strange, painful and very heavy feeling in my stomach that had appeared during the last six weeks of my pregnancy, supposedly caused by the baby's head pressing down, I had felt well and positive the months before. Even after suffering bouts of constipation and being pushed around in a wheelchair when out, because walking was so uncomfortable, did not dim my certainty that my labour would be an easy experience.

I was to have my hopes severely dashed. My waters broke at home, I went into hospital but many hours later my contractions lessened, and it was then that the midwife gave me an internal examination. She diagnosed possible fibroids. I was rushed into theatre to have an emergency Caesarean and awoke later to face the grave expression of a nurse sitting beside my bed. She told me that I'd had a lovely baby daughter and, very soon after, a doctor informed me that the biopsy taken of the supposed fibroid had proved cancerous and that I had a tumour in my bowel the size of a grapefruit.



Josephine pictured with beautiful baby daughter Chloe

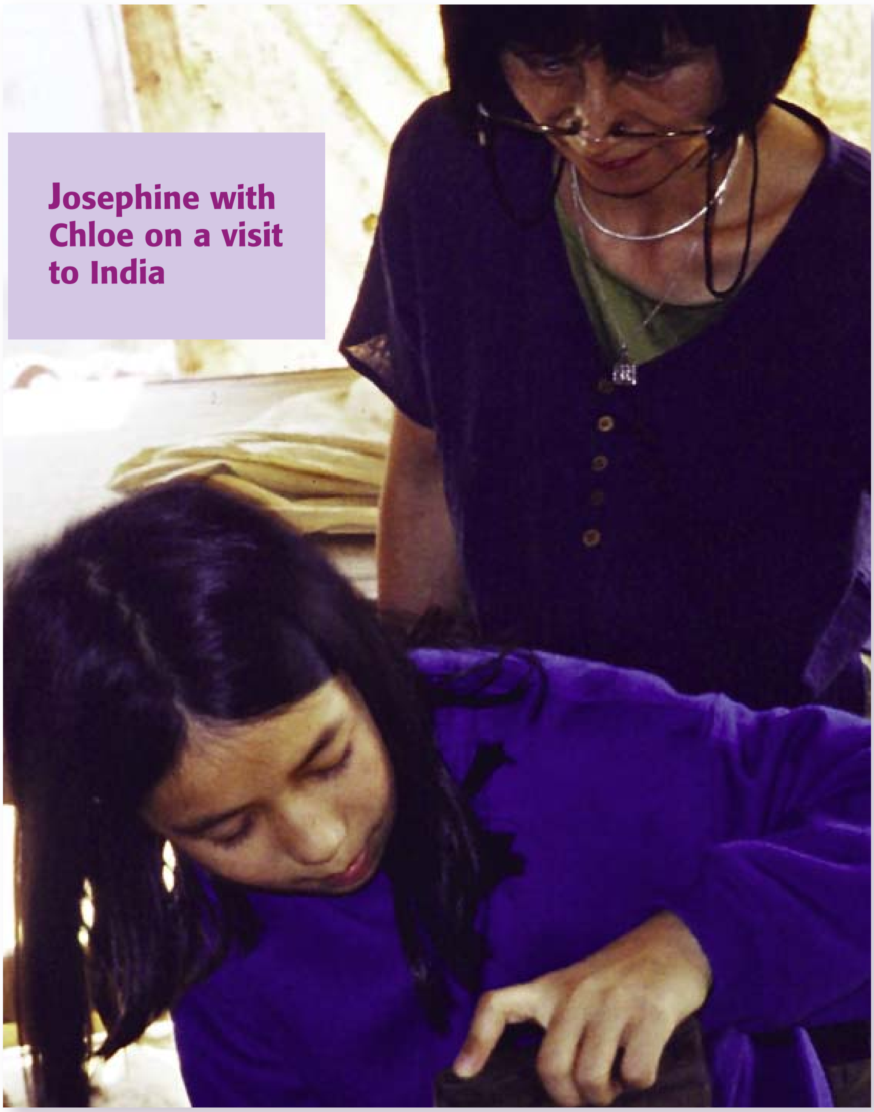
The two different sets of news made no sense to me; all I could take in was that my daughter was healthy and, amazingly enough, completely unaffected by the cancer. I can remember flatly responding that my father had colon cancer and that I must have inherited the condition; it was as though I needed a rational explanation. Later, I also realised why I'd been in such pain just before the birth. The baby's head was pressing down on the tumour, which in turn, had prevented a normal delivery.

A mixed period of euphoria, total denial and shock followed. I concentrated all my energies into looking after this new baby and blocked out the fact that I was going to need to have an operation in six weeks' time to remove the tumour, with possible radiotherapy afterwards. The hospital stoma therapist – a wonderfully sympathetic and humorous lady – explained that I might be left with a stoma and what that would involve, but she could have been talking about moonwalking as far as I was concerned. I could not, would not, take it in. I remember feeling devastated that I would only be able to breastfeed my daughter for six weeks, having fed my other two girls for nine months. My underlying fear and worry of the future was compounded by feelings of inadequacy and guilt that I was going to be unable to look after her, as I would have liked.

At the time, my other daughters were aged fifteen and seventeen – crucial ages in the growing up stage and, in retrospect, I believe they probably suffered from all the emotional turmoil going on and the lack of attention that their exhausted parents gave them. My husband worked full time, so had to sort out post-op childcare and brace himself to the prospect of nightime feeding whilst I was in hospital. How he managed that whilst full time teaching must have required a superhuman effort! My eldest daughter had always been a very supportive and practical person and she quite naturally took to looking after a baby: her younger sister was more vulnerable and less interested in babies.

Eventually, I ended up having two operations to remove the tumour, along with a hysterectomy and appendectomy, a month's radiotherapy and, of course, a permanent colostomy. Largely due to my stoma therapist's care, constant encouragement and home visits, I coped with the stoma but took a very long time to come to terms with having one, not least because my stomach looked like the ravages of a battle field with its huge scars and undulations. I had lost an enormous amount of weight in hospital and found it difficult to carry my baby around. Also, finding the right kind of food, which suited my digestion and new stoma, was no easy task. On the other hand, the shock of being so ill along with the tears and frustration, self- pity and anger, challenged me to look afresh at my life. I determined to nurture body and mind threw myself into holistic therapies, nutritional advice and counselling, whilst taking advantage of massage provided by the NHS. I spent a week at The Bristol Cancer Help Centre and came away feeling totally supported, uplifted and full of positive determination to fulfil my aspirations.

However, it took many years to be able to feel relaxed and unembarrassed enough to let people, other than close friends and family, know about my stoma. I explored the possibility of irrigation and a reversal but felt daunted by the former and was discouraged by the latter when doctors predicted a likely failure. So I concentrated on building my creative self and became a textile artist, an idea I had always cherished.


Josephine with Chloe on a visit to India

I think one of the hardest situations I faced was when I travelled to India on a Winston Churchill Fellowship and had to discreetly mutter to Customs the nature of the "medical supplies" that I was carrying and the fact that I did not want them examined in public! I have yet to use the card explaining that I might need to urgently use a toilet but thanks to the Tidings magazine, I now possess a key for disabled loos. Going to India (I was researching traditional textile techniques which necessitated a fair amount of travelling) was a real eye opener in terms of toilet facilities, and that really was a struggle, along with coping with spicy foods and the odd tummy upset. But I survived, loved the whole experience and would gladly go again equipped with the disposable bags and accessories that I now use and which have made my life as an ostomate so much more convenient.

Twelve years ago, adhesions from my previous operations reared their ugly heads and caused me enormous abdominal pain and vomiting. Eventually I was rushed into hospital, had an emergency operation to remove the adhesions then stayed in intensive care for a week as I had peritonitis and a chest infection as well. I was intravenously fed for about two weeks, lost weight again and felt absolutely ghastly. I had to be very careful about my diet after this – my stoma reacted with intermittent bowel upsets and through patient trial and error, I am now pretty stable and I know which foods to avoid. I aim to eat small portions regularly to avoid wind and bloating building up and also to keep well lubricated, as being constipated with a stoma can be pretty painful!

Living with a stoma has proved most challenging, but has also made me much stronger mentally in that I have determined not to let my condition prevent me from leading an active and fulfilling life. Besides having the continual support from my wonderful family and friends, support has also come from so many unexpected quarters and I have to say that everybody I have met or talked to in the stoma world has been so caring, informative and approachable! I know that there are people walking around with far more debilitating conditions than mine who never complain; my stoma is hidden and I can even laugh about it and, most importantly, talk about it without embarrassment or feeling abnormal. ■

Josephine Ho

Fulicionel Hernia Support Belt

Fulicionel Hernia Support Bespoke Belt

Fulicionel Hernia Support Ladies Bespoke Girdle

Ladies High Waisted With In Built Pouch

Our Patented System

Mens High Waisted With In Built Pouch

Irrigation and you...

Sue Hatton Executive Trustee writes…The Tidings editorial team were delighted to receive this interesting account from experienced irrigator Adrian March. Living in France, Adrian describes how his patient journey as an irrigator has led him to annotate his experiences of irrigation; he also gives us an insight into the French Health Service and patient prescription procedures...

Adrian writes...I expected that the 24th April 1996 would be an important date in my life: I acquired a colostomy. As a consultant in engineering research, a teacher of anatomy, and a very practical person, I was interested to learn more about the physical aspects of my stoma. I soon realised that the only change was that I was disposing of bodily waste through an aperture on my front instead of the usual location. At home, and out of hospital, my stoma care nurse came to visit, and her opening words were: "How do you feel about irrigating?" She got me started, and I've been irrigating ever since: over fifteen years now.

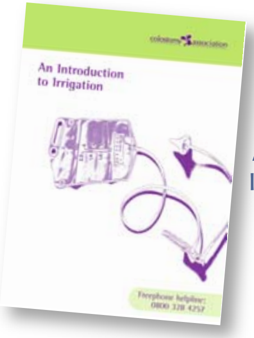
I realised early on when irrigating that there was more to it than had been made out and that impatience is the enemy of successful irrigation! Over the past fifteen years I have been researching the subject on myself, and recording the results. You can read the results on the "Irrigation Notes" page on my website: www.stomadata.com.

I was one of the founders of CA, and perhaps it was an element of publicity associated with that, which prompted consultants, doctors, and nurses to begin referring patients to me for practical and sport-related advice regarding their colostomies. I emailed replies, taking care always to recommend that the patient showed my advice to their medical professional. I documented certain aspects of this correspondence and the resulting articles are on my website.

In August 2006 I decided to move to the south of France, to be able to enjoy the Mediterranean climate, which I had always loved. As a French resident I was eligible for the French Health Service: Caisse Primaire d'Assurance Maladie - CPAM for short. I was surprised to discover that in terms of medical records it is way ahead of the NHS: all my records are stored on a central computer, and I have a card – a Carte Vitale, which looks very like a credit card. The card enables a medical professional to access my records instantly. Treatments and pharmaceutical supplies are not completely free: the patient has to contribute typically 30% to the cost, so most people take out a top-up insurance, a mutuelle. However, those with conditions 'of long duration' or permanent, like colostomies, receive most of their needs free.

A patient registers with a doctor in the just same way as in the UK, and prescriptions for commonplace requirements are issued in the normal way, but colostomy needs are not commonplace, and it is helpful if the patient does some homework in advance. This involves finding the code - the ACL number - by which the various products are known to CPAM; usually available from the manufacturer of the item. A prescription is issued covering requirements for three months, and for stoma needs a duplicate is provided, which can be used up to three months after the first, so that a visit to the doctor is required only every six months. There are no home delivery services in France: all the products have to be obtained from a Pharmacie. As a corollary of this, there are no free disposal bags or wipes; these have to be obtained from a supermarket, and apparently no such thing as medical adhesive remover. It is with irrigation that one encounters the big difference. It is not simply that colostomy irrigation is not taught: the medical profession strongly advise against it, and claim that it is dangerous and should only be undertaken by a medical professional. Fortunately my doctor understood that I knew what I was talking about, and was happy to copy and sign what I had written out. Interestingly, colostomates in France who have appealed to me for help, and to whom I have emailed a suggested prescription, have encountered no further trouble with their doctors, so I am inclined to surmise that irrigation, in the sense that colostomates know it, is simply not taught to the profession, who in turn are not prepared to support something they know nothing about.

Editors Comment



If you would like a copy of our leaflet An Introduction to Irrigation or would like to share your irrigation experiences or have any hints or tips

please contact us
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or write to:
Colostomy Association
2 London Court East Street
Reading RG1 4QL
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0118 939 1537

Are you about to have a Colostomy?

Some time ago I chatted to a lady on the CA helpline, she was in a quandary as to whether she would or should have a colostomy. I asked her why; she revealed she had been diagnosed with a fast growing cancer that was affecting her stomach and colon. Her medical team advised removal of the colon and said that a colostomy was necessary. She explained that her team had asked her if she wanted to go forward with the operation. She was left to contemplate her situation, hence her call to the helpline.

It seems that once diagnosis is made by the consultant/surgeon – the patient is asked to decide whether they wish to go ahead with their colostomy operation. Most patients seemingly are left not knowing how to make a decision that could change their lives forever.

Has the above happened to you or are you facing this dilemma right now?

Taking a decision to have any surgery can be difficult, the best option is to talk it through with friends and family and keep talking. An open mind will help you decide what is right for you. Being armed with the correct information will help and this should always come from a medical professional. Never be afraid to ask your team questions, they are there to provide you with help and support. Having been told the facts about your illness/condition in the cold light of day isn't always easy to deal with. You may feel overwhelmed or you may feel the need to take some control over your prospective treatment and care.

So, the following may help when visiting your consultant/surgeon, stoma care nurse or GP:-

- If possible try to take a member of your family or close friend along to your appointment – it is difficult trying to remember everything yourself, they will pick up on things that you might miss.

- Write out one list of questions to ask and make a duplicate. Take a pen and the two lists with you, give one to the oncologist (surgeon) and retain one to read from and make notes on. You can revisit your list when you get home, it will help to remind you of the conversation.

What questions should I ask?

The following is a list of sample questions, which may help you outline your own.

- Can you tell me how far my cancer (crohn's disease, diverticulitis etc.,) has spread and why it is necessary for me to have a colostomy?

- If it is cancer, will I need chemotherapy or radiotherapy before/ after the operation?

- If I do have to have a colostomy, who will perform the operation and what is the success rate?

- Can you tell me the risks associated with this operation?

- What is the outcome for patients following this kind of operation?

- What is the general recovery time following this surgery?

- What can I expect pre-operatively and who will take care of me post operatively?

- Will I have access to a stoma care nurse – before and after the operation?

- Will I be taught self-care and how will I receive my medical supplies (pouches etc;)?

- Will I be able to have the stoma reversed?

- How will I manage my bowel evacuation? What options are there?

- What happens when I return home?

How do you prepare yourself for 'living with a colostomy'?

The Colostomy Association is there to support, reassure and encourage those who are experienced colostomates and new to 'living with a colostomy'. The Association has a range of support services and written information that can help you. However, there is no greater reassurance than talking to or meeting someone who knows how you feel. If you need this kind of support our Freephone helpline is available on: 0800 328 4257. You can talk to a trained volunteer who may be able to answer your questions or if not will refer you back to your medical team.

Your medical team includes a stoma care nurse. He/she will guide you through your journey and explain everything in detail from where your stoma will be sited to how to take care of it. Your tummy will be marked with a pen before the operation to ensure that the siting of the stoma will be as unobtrusive as possible. Your stoma care nurse will discuss the various appliances available to you and may even chat about the possibility of colostomy irrigation.

There are so many products out there for ostomates – deodorisers, adhesive removers, barrier creams, solidifying agents and many more. Specialist and attractive underwear/nightwear and support garments are also available.

You will receive your colostomy for a very good reason and once you have recovered from the operation you will be able to take up your life once more. A colostomy should never hold you back from anything.

In some cases it may be possible to have your colostomy reversed after your body has healed. Your surgeon will advise on this but do try not to put your life on hold thinking that this is the only option. Living with a colostomy is different but not impossible.

Someone once told me – a stoma is like having to look after a baby. At first you really don't know what to do – but it becomes easier – you manage to look after it and let it enhance your life.

Jackie Dudley
Trustee, Colostomate &
Helpline Volunteer

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Parastomal Hernias...

are they a compulsory, additional disfigurement for Colostomates?

Sue Hatton writes…there has been a marked increase in the number of patients contacting the Colostomy Association surrounding hernia development around the stoma. As Executive Trustee I feel compelled to find out why and to see if there is anything that can be done to improve patient outcomes and quality of life. In the first of a series of articles around 'living with a parastomal hernia' I have decided to investigate this abdominal protrusion.

What is a parastomal hernia?

The term parastomal hernia is used to describe a bulge or swelling around/under the stoma that leads to problems with stoma function and appliance security. This usually occurs gradually and the hernia may increase in size over time. When a stoma is created, the surgeon generally brings the end of the intestine out through the abdominal muscles, which provide support for the stoma. By making an incision in the muscle, a potential weakness is created. A parastomal hernia can occur when the edges of the stoma come away from the muscle, allowing abdominal contents (usually a section of bowel) to bulge out. Surveys have reported that, over time, up to 70% of ostomates develop a parastomal hernia; the longer a stoma is present, the more likely it is that a hernia will occur. Not all hernias give rise to symptoms.

What causes a parastomal hernia?

There are many factors that contribute to the development of a parastomal hernia including:

- Coughing and sneezing.
- Straining: this can happen when lifting heavy objects or during strenuous activities such as gardening.
- Infection at the site of the stoma or abdominal wound.
- Muscles becoming weaker with age.
- Being overweight.
- Poor siting of the stoma.
- Emergency surgery.

What problems can a parastomal hernia cause?

Some people complain of a dragging and dull ache around the hernia, especially at the end of the day or when they have been particularly active.

As the hernia increases in size, the shape of the stoma can change making it difficult to attach a pouch, which may cause problems with leakage. The surrounding skin can become tightly stretched and may become quite fragile making it more susceptible to breaking down or being torn when the pouch is removed. A hernia may affect stoma irrigation. It can become more difficult or time-consuming to introduce the water. The resulting output may be less satisfactory. Understandably, the larger the hernia becomes the more difficult it is to conceal beneath clothes and this can cause embarrassment.

What is the treatment for a parastomal hernia?

First line treatment is to wear a firm stoma support garment. There is a wide selection available in the form of belts, girdles, pants or boxer shorts. A stoma care nurse can advise on the most suitable support garment for you. Improvements in the tone of the abdominal wall through exercise or Pilates, aimed at strengthening the core muscles, may help. Most parastomal hernias do not require surgery. However, if the hernia is causing pain and/or becoming unmanageable, surgery can be considered. As with all operations that require an anaesthetic there are associated risks. Surgery, therefore, may not be recommended for those who are elderly and infirm or those with serious heart or breathing problems. Having a hernia repair does not guarantee it will not recur.

There are different methods of repairing a hernia: some will be carried out through an incision in the abdomen (open surgery) others can be done by keyhole surgery (laparoscopically). A tissue repair at the site of the hernia is a relatively simple procedure, but there is a high risk of the hernia recurring. Repair and re-siting of the stoma to another location on the abdomen is a bigger operation involving a larger incision, but the chance of the hernia recurring is lower. Repair and reinforcement of the hernia site with mesh carries a very small risk of infection but the chance of the hernia recurring is lower. When considering an operation to repair a parastomal hernia always ask the surgeon about the technique that they propose to use. Only have surgery if the first-line measures have not worked or if you have been admitted to hospital with a complication.

Can parastomal hernias be prevented?

Below are some suggestions, which may reduce the likelihood of developing a hernia:

For three months after surgery…

- Avoid heavy lifting
- Support your stoma and abdomen whilst coughing

And then…

- Try to maintain good posture at all times, consider Pilates
- Avoid heavy lifting whenever possible, but if you have to lift something remember to:
  - wear a support garment (Belt or underwear)
  - place your feet apart (one foot in front of the other), keep your back straight and bend your knees
  - keep the object you are lifting close to your body
- Wear a support garment if you are doing heavy work e.g. decorating or gardening
- Avoid gaining weight, or try to lose weight if you need to
- Take regular exercise e.g. walking, swimming
- Pilates is especially suitable for ostomates and particularly good for developing stronger abdominal muscles.
- It is best to avoid high-impact exercises, which involve hard jolts to the body e.g. football or squash
- It is important to check with your surgeon or stoma care nurse before undertaking any exercise programme

Sue continues…to learn more about patients 'living with a parastomal hernia' I have asked Salts Healthcare to write an article for Tidings based on their recent major research study amongst ostomates in the UK. (All questionnaires received and analysed were sent in from people who had diagnosed hernias from healthcare professionals). So please look out for this in a future issue. The following paragraph gives a précis of the content and direction of the survey.

The reasoning behind conducting the research was to improve the understanding of the experiences of patients ‘living with a parastomal hernia’. The survey was particularly interested in the condition of the skin, and the changes to skin condition once a hernia has developed. The amount and frequency of leaking, the change to the size of the stoma once a hernia has developed, and whether ostomates needed to change to a different appliance because of the hernia. The project also studied the time it took a patient to develop a parastomal hernia and the incidence of further surgery to repair the hernia and re-site the stoma. Also, important to the study was to look at ways in which the parastomal hernia affects people and whether ostomates were seeking any help to manage their parastomal hernias.

I am convinced this study will provide us with a clearer picture of those ‘living with a parastomal hernia’. Being an inquisitive soul and passionate patient advocate I too have a series of questions…that might provoke comment or perhaps answers from Tidings readers’ and healthcare professionals alike…read on:-

- Does the patient get enough warning about the possibility of herniation?
- Should a patient be automatically fitted with a support belt and given a leaflet on prevention? (Is there opportunity for the stoma care nurse to spend enough quality time with patients, following surgery and does the patient fully absorb the information supplied).
- Can weak stomach muscles mean a parastomal hernia is inevitable - could this be prevented if the patient is given an exercise plan prior to elective surgery?
- Is a parastomal hernia due to a lack of inheritance of good genes or is it just down to luck that some of us have perfectly formed stomas and no hernias - 70 % of colostomates have to cope with this additional burden – why?
- Is the marked increase in the number of bowel operations, an indication of the surgeons meeting targets and not considering the patient’s quality of life following surgery?

And to finish a thought provoking email addressed to the Colostomy Association…

Dear Chairman and Trustees of the Colostomy Association,

I write about the vexed issue of parastomal hernia. In general that the incidence of parastomal hernia is very high; it is believed that end ileostomy has 16% parastomal hernia rate, colostomy has 24% parastomal hernia rate. The recurrence after repair of parastomal hernia can range from 10% to 77%.

Even with stomas brought out through a prophylactic mesh results in 5% recurrence rate in 1 year and 13% recurrence rate in 5 years. However, what really fascinates me is that In 1977 it was published in the journal Disease of Colon and Rectum, American surgeons found that in 106 patients they had 0% parastomal hernia rate - no parastomal hernia - when the colostomy was brought out through the umbilicus (with an overall complication rate of 3.9%) (Raza SD, Portin BA, Bernhoft WH. Umbilical colostomy: a better intestinal stoma. Dis Colon Rectum. 1977 Apr;20(3):223-30).

Sometimes we forget to learn the lessons from the past. My personal view is that this is mind blowing. Given the anatomical and evolutionary fact that intake and output orifices are in the midline (including the umbilicus before we are born), it now strikes me as strange why surgeons ever thought of placing stomas away from the midline. The difficulty for open surgery in current practice would be the non-availability of the umbilicus because of the mid-line incision.

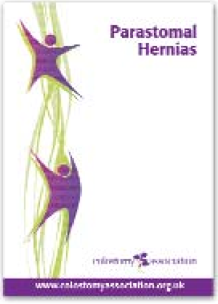
However, with the advent of laparoscopic surgery, the umbilicus is now available for stoma placement. With a published 10% to 70% parastomal hernia rate and up to 77% recurrence of repaired parastomal hernias, the resources taken up in dealing with these are enormous. The impact on patients are profound. It looks like we could have a winning situation for everyone if we placed end stomas through the umbilicus. We could have dramatically better results.

No one currently places stomas through the umbilicus. Some patients I have spoken to have said they would not mind this but others were not so sure. I wondered if the Colostomy Association was aware that a 0% parastomal hernia rate was possible in the past. I wonder what the Colostomy Association's view is on umbilical stomas.

Kind regards and best wishes,

M. HEMADRI MBBS (Madras) FRCS (Edinburgh) MBA (Leicester)
Clinical Innovation and Improvement Lead Associate Specialist in General Surgery Northern Lincolnshire and Goole Hospitals NHS FT Fellow, NHS Institute for Innovation and Improvement - 2009

PS: *I have no vested interest in this issue. My aims are to explore all options for enhancing patient experience, reducing complications and sparing resources.*



A booklet is available from the Colostomy Association entitled ‘Parastomal Hernias’ to obtain a copy contact general enquiries on: 0118 939 1537.

If you have found the content of this article interesting or have your own questions and experiences of ‘living with a parastomal hernia’. Please get in touch with the editor at: editor@colostomyassociation.org.uk or via cass@colostomyassociation.org.uk.

Note: The CA offers a 24hr Helpline run by dedicated trained volunteers who are colostomates – it is available to everyone ‘living with a colostomy’, and to their families and their carers, please contact: 0800 328 4257. If you have any issues or concerns about your stoma contact your GP or stoma care nurse.

Reference: Parastomal Hernias Booklet 2011 – produced by the Colostomy Association in association with Mr Ian Daniels FRCS Consultant Colorectal and General Surgeon, Royal Devon & Exeter Hospital and Jo Sica RGN, ENB216 Clinical Nurse Specialist, Stoma Care.

A Colorectal surgeon's first-hand experience of the impact of a stoma on a patient's life...

Dad and me a year before his surgery on a ferry to France

Trained in colorectal surgery over a decade ago I have found that the moment you mention bowel operation to a patient, they ask if it involves a stoma or 'a bag'. There is no doubt that a stoma, whether temporary or permanent is a life-changing event for a patient which presents a new set of challenges not only to them but also to those who surround them.

I have formed many stomas for patients and offered them advice and reassurance. In 2002/3 I was responsible for a study that initiated the concept of teaching patients how to manage their stoma pre-surgery rather than post-surgery. It was therefore a twist of fate, when last year in May I had to refer my father to a colorectal surgeon for a colostomy operation.

A retired Naval Officer, my father had never experienced more than a few days off sick whilst on active service or off duty. He was a fiercely independent and self-confident individual who unfortunately for the last year has had complications with infection from radiotherapy for prostate cancer that has since been cured.

My father had his stoma surgery in Birmingham and lived with me whilst he recovered. He was unfortunate to have suffered multiple complications.

During his stay with me I realised the impact a stoma has on a patient's life and the practical issues associated with it that as a surgeon I had never experienced before.

The bowel brought up as a stoma seemed very normal to me. It was different for my father, he was nervous and tentative in the way he cared for and managed his stoma. The stoma care nurses had taught him well as he developed a set routine and managed his bag changes proficiently. However, at the slightest twinge of pain or bit of bleeding whilst it healed was reason enough for him to seek a consultation with me 'his son – the surgeon'. I wondered about all those patients of mine who similarly, would have had questions or faced dilemmas. I pondered over who would have sorted them out.

A few months after his stoma surgery, fate again dealt him a cruel blow; he started to develop a parastomal hernia and a significant stomal prolapse. I had to try and explain what had gone wrong and why this was happening – treatment of these problems is difficult. He was not well enough to have more surgery. I realised that both problems were impacting on his overall confidence – common occurrences – his stoma bag wouldn't stay in place and there was leakage.

I remember the first episode of diarrhoea which caused his bag to burst and come off whilst we were at my brother's house. He was so upset, the embarrassment of having soiled the bed sheets in his son's house, my mother's failure to understand that this was just an unfortunate incident that could not have been prevented, all contributed to a very depressing day for them both.

My dad and I travelled to Australia this year and it offered me the opportunity to learn about the travel arrangements a patient with a stoma has to plan for in respect of looking after their stoma. I was surprised to have to explain to the baggage scanners and customs officials what the blue bag (containing the spare stoma bags, adhesive remover spray and wipes) was all about. I did however feel reassured that we had specific stoma appliances that could in part be flushed down the toilet which removed my concerns of disposal.

It has taken my father a while to get used to his stoma but he has coped well and has recently gone on to have another stoma created for a urostomy. His journey offered me a real insight into the life of a patient 'living with a colostomy' and has definitely made me wiser.

I have also realised the problems that result from a prolapsing stoma and parastomal herniation and what a patient has to contend with. This experience has influenced my approach to managing them.

Whilst I realise that stomas created during emergency operations save lives and are unavoidable, there is an opportunity to better prepare patients for stomas that are planned for – 'elective' surgery. As I mentioned earlier I was responsible for a study that initiated the concept of teaching patients how to manage their stoma pre-surgery.

This year at the University Hospitals of Leicester, we are pleased to have recently completed a patient information video that explains stomas and how to manage them and we look forward to offering them to patients and studying the benefits.

Mr. Sanjay Chaudhri
Consultant Colorectal
& General Surgeon
Leicester General Hospital
University Hospitals Leicester NHS Trust

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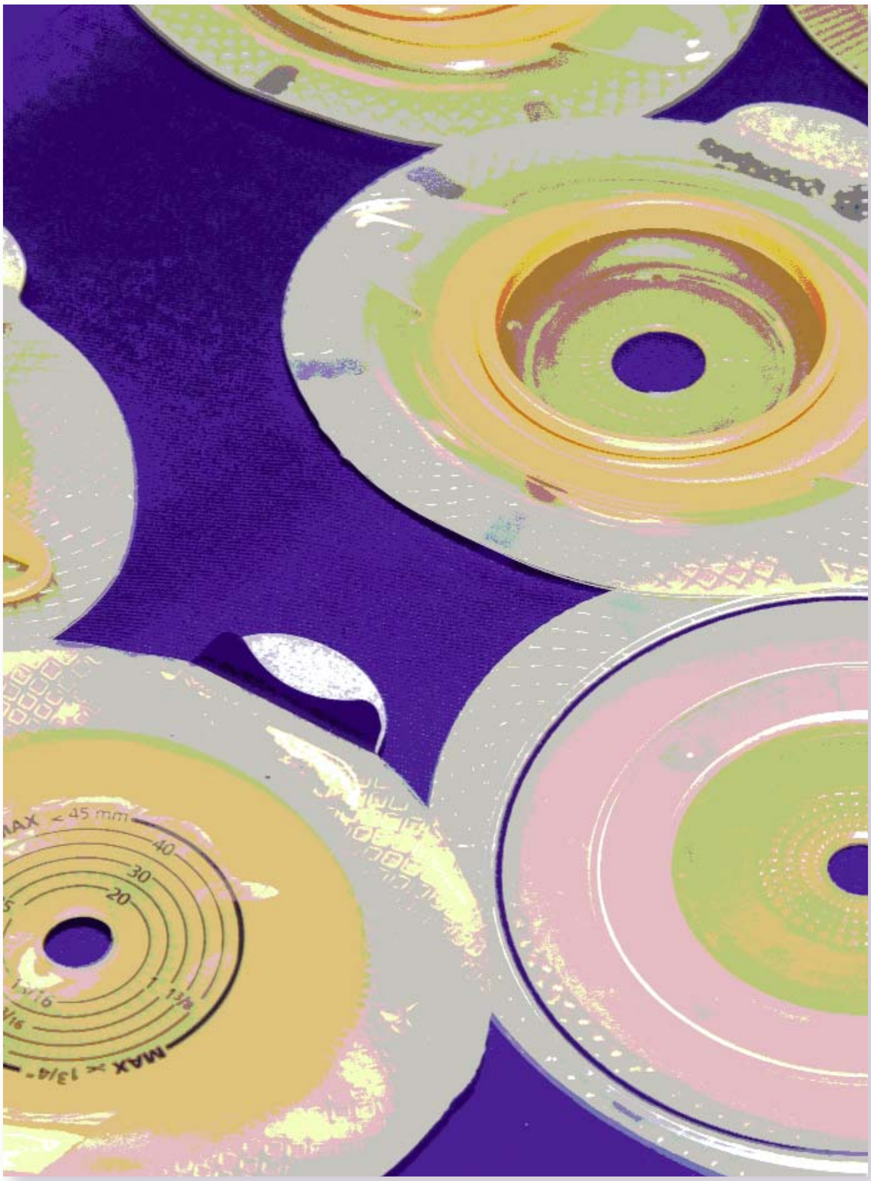
Disposal of used appliances...

A personal experience

Associate-Editor, Rosemary Brierley... takes a look back at how she has coped with the problem of disposing of used pouches over the last twenty years, and points out the disposal options available to ostomates today...



While I was still in hospital, way back in 1990 - just a couple of days after my colostomy surgery - my stoma care nurse taught me to empty my pouch before I disposed of it. She showed me how to hold my one-piece closed pouch over the toilet, cut the bottom off and give it a good shake so the contents fell out. Then she held the hole in the flange under the flush so the water ran through the pouch and out the bottom, thus rinsing it out. The next time I had to do this myself!

When I talk to ostomates who have had their surgery more recently I find that very few of them have been taught to do this. I suspect this is because stoma nurses feel that this is a lot to ask of patients who have just had major surgery and are still struggling to come to terms with having a stoma. Nurses may also have concerns about hygiene. Twenty years ago I thought this too…but I did as I was told.

The nurse showed me two kinds of disposal bag: one made of semi-transparent polythene and perfumed, the other of thicker grey plastic and self sealable. I chose the latter because my emptied and rinsed pouch could be rolled up and sealed inside it making a thin, discrete package which my stoma care nurse said I could dispose of with the household rubbish.

However, if I wanted, she could contact the environmental department at the local council to arrange for the domestic clinical waste collection service to call at my home. They would provide me with a "yellow bag" in which I could put my used pouches and they would collect it the following week. This service is invaluable for ostomates who find it impractical or unacceptable to empty their pouches. However, unfortunately it is not available in all areas.

I decided that the pouch I was disposing of was cleaner than a baby's disposable nappy, so I would just put it in the dustbin as the nurse had suggested. But what about hygiene issues? Of course once the process of emptying and rinsing was complete, I washed my hands thoroughly with antiseptic liquid soap (I know some ostomates who prefer to wear disposable gloves). The output from my stoma tends to be quite thick and often sticks half way down which makes cutting the bottom off the pouch much easier. However, I kept scissors just for this purpose and if they did come into contact with the faeces made sure they were disinfected. Some ostomates prefer to cut the top off their bag as this is usually clean.

And so I continued - emptying and rinsing the pouch, sealing it inside a disposal bag before putting it in the bin…for the next fifteen years. This has made it so much easier when I have been away from home. On holiday in a hotel I just disposed of my discrete package in the pedal bin in the bathroom (first concealing it inside one of those small paper or plastic bags labelled "for disposal of sanitary products" if there is one). While staying with friends or relatives I just placed it inside a carrier bag before taking it outside to the dustbin.

At home, for many years, every time I changed my bag I would troop outside, sometimes barefooted, to the dustbin. Then I discovered the nappy disposal unit, which enclosed my package within a polythene film. I now have one in the bathroom so trips outside in the rain and snow, or the middle of the night, are a thing of the past.

But that's not the end of the story: About three years ago I changed to flushable pouches. I had resisted this before because I live in an old house and I was worried that the ancient plumbing and drains might not cope. However, touch wood, I've had no problems. If the liner doesn't flush away first time, I pour a large jug of water into the toilet bowl at the same time as I "pull the chain" for the second time. I still have my nappy disposal unit in the bathroom for disposing of the outer plastic pouch and it also comes in handy when the tiny grandchildren come to stay!

Now the only time I don't use a flushable is when we go cruising. I am not prepared to take the chance that they might cause a blockage in the fine bore pipes. So what do I do? Well I don't relish going back to cutting the bottom off my closed pouch. Therefore I use a two piece system, because the hole in the pouch where it sticks or clips onto the base plate is much larger than the stoma-sized hole in a one-piece. It is relatively easy to empty and rinse out through this one hole. The drainable bags, I take with me in case of a stomach upset, are designed to be emptied and so don't present a problem.

So that's how I've coped with disposing of my used pouches for the last twenty years. So what is my message to the manufacturers for the next twenty? Pouches that are easier to empty or have flushable liners, please, so that we ostomates can dispose of our used appliances in a convenient, hygienic and eco-friendly way.

Rosemary Brierley
Associate-Editor

Note: This is a purely personal account. The CA believes in making ostomates aware of all the options for the disposal of used appliances, so that we can all make an informed choice about which method is most suitable for us.

Disposing of used pouches – the options...

A stoma care nurse or district nurse can arrange for the environmental department at the local council to provide you with clinical waste bags which they will collect at regular intervals.

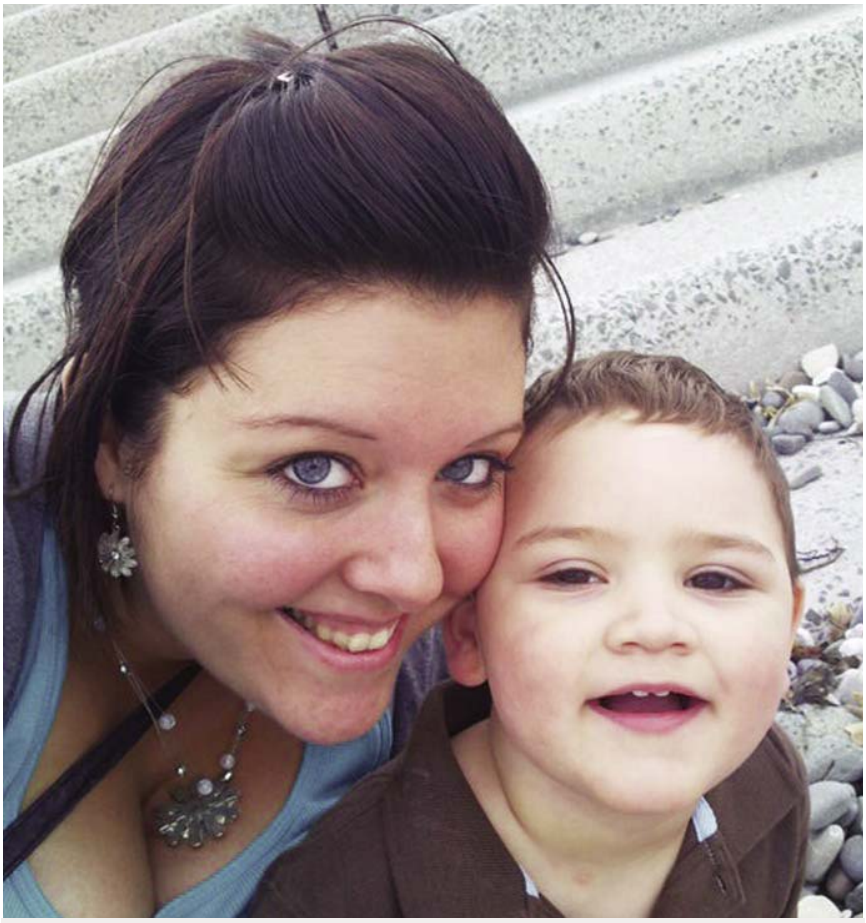
The contents of the pouch can be emptied down the toilet before sealing the used pouch inside a disposal bag and discarding it with the household waste. (For those who find emptying the pouch difficult to deal with and live in area where there is no domestic clinical waste collection service, the pouch may be double wrapped before placing in the dustbin.)

Drainable pouches can be emptied which means that not so many are required and they can be easily disposed of in the household waste.

Flushable bags have a liner which contains the waste and can be flushed down the toilet. The clean outer pouch can be disposed of with the household waste.

Ostomy Lifestyle Underwear & Swimwear Show 2011 – A Positive Living Event...

Ostomy Lifestyle's flagship charity event will be at Birmingham Town Hall on Wednesday 2nd November...twelve models with stomas will be promoting a positive image of life after stoma surgery. Images from the 2009 show have already provided inspiration to thousands of people with stomas in the UK and around the world and this year's show will reach even more!



Hayley-Jade Brown pictured with her son had her colostomy after her bowel perforated during a caesarean section...

Hayley-Jade Brown, 25 from Blackpool, had her colostomy after her bowel perforated during a caesarean section 3 years ago. "I had never even heard of a colostomy before my operation and was so poorly afterwards it was a while before I realised what had happened. I came home from hospital on Christmas Eve so between that and the fact that I had a new born baby son, cerebral palsy, the stoma had to fit in around me, after all this is my 'new normal' so I just decided to get on with it.

My body image has definitely changed since having a stoma. In some ways I'm less confident as my tummy area is covered in scars from the operations which I don't like, but in other ways I'm more confident, I now have a greater appreciation for bits of my body that I never used to like. My partner says that he doesn't even notice the bag anymore and I'm happy to go on the beach wearing a bikini now, which I wouldn't have done before!

Being involved in the Underwear and Swimwear show is my way of saying to the world – 'I'm happy with who I am' and it's a great opportunity to explain more about my colostomy to my friends as I think they've all been a bit scared to ask before!"

Video interviews with Hayley and all the other models are on the Ostomy Lifestyle website.

For more information and tickets visit: www.ostomylifestyle.org or call 0118 324 0069.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breakaway
putting smiles on young faces

Can I really go swimming...Yes! You can!

A common question often asked after surgery is 'Can I go swimming?' The answer is of course you can...Breakaway decided to tackle this question head on to demonstrate to both parents and children that swimming is a fun activity they can return to and enjoy! Here are their comments and experiences...

Having been associated with Breakaway since its inception – as an attendee and now as a Professional Volunteer – Breakaway events never cease to amaze me. I come home uplifted by these wonderful children who give so much to each another!

For the past two events we have taken the children swimming, the hour long session is so much fun! I know from experience that some swimming pools refuse children with a stoma permission to swim due to 'Health & Safety' issues!

For children with a stoma to have the swimming pool completely to themselves without fear of "Who will see my bag", or being looked at differently is fantastic! To hear a young teenager say, "It's the first time I've worn a bikini", fills you with emotion.

After one pouch coming adrift, I merely cut a new one at the poolside for a little boy and his Dad changed him in the changing room…no problem!

These children deserve to be included in everything and that's just what happens at a Breakaway-Visits Weekend!

Lesley Nickel
Stoma Care Nurse & Breakaway Professional Volunteer

Our son was a confident swimmer looking forward to doing his pool lifeguard qualification, and then he became ill and very soon had an ileostomy. At 15 years old he felt uncomfortable going to the pool with his bag, and only attempted to swim on a couple of occasions – always afraid that the worst would happen – his bag would come off! That was three years ago. We have attended Breakaway's swimming sessions...they are great for all the children! To experience swimming with the other children boosts the children's confidence especially when they return home and go to school swimming sessions or public pools. It's so important that the children experience the benefits and joys of swimming!

Alison - Breakaway Parent

My son Michael is 9 years old and has a colostomy, when we usually go swimming Michael wants to wear shorts and a top as he worries that people will stare. Michael always worries about whether his colostomy bag will come off or break. I try and build up his confidence when swimming but it doesn't seem to help much.


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When Michael went swimming with the other Breakaway children...after ten minutes, he took off his top and was in and out of the water in just his swim shorts! He didn't check his bag once! Michael's words after swimming were 'Fantastic, everybody was the same mummy. It was so much fun'.

Breakaway, has helped us as a family to deal with day to day issues that arise in our lives and I would like to take this opportunity to say a huge thank you to Breakaway.

Lena - Breakaway Parent

I am a parent whose child has a bowel disorder. The children and parents alike, including me had a great time splashing around! Since then I have offered to become a volunteer for Breakaway that includes being thrown in at the deep end!

Chris – Breakaway Parent

Swimming with my new friends at Breakaway helped me see I can do all the stuff I used to do. We jumped in, had races and water fights and it was brilliant! I am going swimming with the school for the first time along with my school friends and I'm not worried anymore because I know I can show everyone what a brilliant swimmer I am.

Will – Aged 9

Before I had my surgery in 2008, I used to be like a fish; I loved swimming! I did stamina and synchronised about three times a week. However when I had my surgery I lost my confidence and didn't go back to my swimming. I was worried about leakage. (However I have now found a product – ' seals', they are like extra flanges, which have given me extra protection and extra time to get to a toilet).
My experience with Breakaway has taught me to not to worry about what other people might think about my ileostomy and me. Everyone needs time to find their own way of dealing with their stoma, having good friends or an adult/teacher who understands can really help. I enjoyed swimming with my new friends at Breakaway it has made me more confident and I look forward to swimming next time.

Alice - Aged 16

Swimming is always a major concern for anyone who has recently undergone surgery, but for ostomates it can be more of a worry. I think my biggest concern was my bag's adhesive coming loose, as it would result in a big and embarrassing drama that every teen would want to avoid!

Hannah chats...

I am not scared to go swimming with my ACE and Mitrofanoff now, but when I first had them I wouldn't even sit in the bath with water covering them, I thought I would sink!

I love going swimming and it was good fun helping the little ones at Breakaway. Some of the older children kept trying to splash me, but I just splashed them back even more!

Hannah
Aged 10

In addition to that there's the worry of someone spotting my bag and commenting about it. Swimming with Breakaway gave me a lot of confidence, it allowed me to swim freely without worrying about what other people might say about my bag and that made me feel normal. It made me realise that swimming with a bag is actually a thing I can do on a regular basis and that the bags are actually safer and more robust than I thought. I really enjoyed swimming at Breakaway there were so many of us that we ended up splashing each other it was great, rejuvenating experience that finally let me put some of my worries behind me.

A great tip I have for any other teen boys out there is to wear swimming shorts and make sure they're tight enough to go over the bag. This allows the bag to be hidden away and stops you from worrying about it. Also, if you are worried about the adhesive getting loose you can order strips to go over the edges, which helps to protect the adhesive from getting loose and creasing.

Joshi - Aged 18

More information about Breakaway...

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Travelling through Airports...

The article in the last issue of Tidings resulted in several e-mails and letters from readers who also felt embarrassed and upset by treatment from security staff at airports in this country and abroad. Thank you to all those who contacted CA head office and Tidings editor...

We are planning to collate this information and present it to the British Airport Authority (BAA) and the Civil Aviation Authority (CAA) in the hope that we can work together to raise awareness among airport staff.

In case any readers have had second thoughts about travelling abroad after reading about Barry's experiences at Southampton airport we would like to say that very many thousands of ostomates pass through airport security every year without encountering any problems.

We received this e-mail from Duncan Wells, Radio & Television voiceover artist and owner of a sailing school in Buckinghamshire. Many of you will remember that Duncan wrote in Tidings issue 12 about how a faulty flare exploded inside his abdomen causing massive internal damage and resulting in a colostomy. Duncan has also spoken about his experience at the last two CA Open Days.

Duncan Writes:

I have been given the once over search on a number of occasions where they pass their hands over your clothed body and on each occasion when they have felt something strange – the colostomy – they have reacted with great embarrassment and apology. I have told them not to worry and I go on my way.

I imagine if they were pursuing something metallic which had come up on their screens they would want to go further to investigate. If they wanted to search further I would simply suggest that I would change my bag in front of them if they really wanted to look and they could take the old bag and know that there was nothing there. Do they imagine that we might stick something into the stoma, like drugs – the way the drug dealers do when they stick things up their bottoms? Telling the security people that sticking something up the stoma would have it come out in a few seconds might help them to understand that this form of concealment is fairly pointless.
Far from being embarrassed ostomates ought to say, "Certainly if you want to watch I will change in front of you. It won't be nice but it is up to you, if that's what you want." I of course have an added weapon if you like in that I would warn them before I raise my shirt that, "What I am about to show you is likely to have you in therapy for the rest of your life, but if you think you can take it, let's do it." They've been fine with me so far but I can see that they would be persistent if their machines say there is something there and they can't find it. It's their job to find things.

Anyway one can be an ordinary boring tourist or one can be an ostomate who is suspected of being a terrorist, much more interesting. But don't for goodness sake fight them or argue with them. Do exactly as they ask and be helpful. Indignation won't get you anywhere except bounced off the flight and where's the fun in that?

We also received the following letter from Cyril Smith:

I have had my colostomy since May 1989 and first travelled abroad by plane in 1993. Since then I have been to either Europe, North America or Canada by air at almost twice each year, with a total of about 30 flights altogether. This means I have passed through airport security some 60 times during which, I have experienced three incidents, which are worthy of mention.

The first was in the mid-nineties, when airport security was a lot less onerous than it is today. It was in Spain, where young persons dressed in military uniforms were carrying out a sort of body search. The man who I encountered looked suspiciously at my waistline and motioned for me to lift my shirt whereupon I just glared at him and shook my head. At the same time my wife and sister-in-law shrieked "no way" and he just gave up. I did try to show him the page in Spanish, in the travel certificate I was carrying, but he was not interested. Since 9/11, things have been much different, particularly in America and my second incident occurred at Los Angeles airport where the security officer questioned the bulge under my shirt. I told him it was a colostomy but he wasn't sure what this was and asked if he could see it. I told him he could but we would need to go somewhere more private. He took me to an office where other security staff were present and said he would ask everyone to leave if I wished. I said this was not necessary and showed him what he wanted to see. I was very careful to ensure that he did not touch anything.

Thirdly, at a Canadian airport, the security officer wanted to know more about my situation and again, asked me if I would show him. As before I said I would, providing there was somewhere private where we could go. This time he got another officer to accompany us and he found a vacant room for me to show him. The other officer stood by the door whilst this was carried out.

In both of the latter incidents I must say that I was treated with the utmost courtesy and understanding and thanked for my cooperation. In addition, to the forgoing I have been asked many times as to what is under my shirt and when I have said what it is this has been accepted. However, sometimes I have to say in Basic English what the bag contains!

These events have caused me to look at the problem of having a colostomy during security check situations, from the point of view of the officials who carry out this task. They have thousands of people coming past them and they only have a brief opportunity to ensure the safety of passengers is maintained. Therefore, it is essential to assist them (and yourself) as much as possible. Although the CA policy is to have a medical person present if a body search is carried out, I consider that this is only necessary if one is asked to remove a pouch or the official wants to do more than look and see. However, as mentioned in the Tidings article, most times no medical person is available.

How we present ourselves for scrutiny needs to be considered and consequently I have devised a brief list of the points I personally consider important they are as follows:-

- Before joining the queue at the

security check, visit the toilet in order to ensure that the colostomy pouch is as empty as possible.

- Remove all metal objects from your pockets etc. including spectacles and belts (I wear braces which makes this more difficult), as these get you noticed and therefore subject to a body search.

- Be polite but firm if asked to display what lies beneath your clothing and insist that you are taken to somewhere private. This would be the appropriate time to show your travel certificate and/or a Doctor's letter, if available, as they may help you to avoid a further search.

- Before agreeing to this, ask the official to collect your belongings off the conveyor belt and to hand them to a member of your party, or store them safely on your behalf until you return. This is most important especially if you are travelling alone, as it is quite easy for someone to help themselves to your effects.

- Be prepared to show the security person whatever he or she wants to see but make it very clear if you wish, that if anything is to be touched or removed then you expect a medical person to be in attendance.

- If you are concerned about the treatment you have experienced and feel that you should make an official complaint, then try to obtain the name of the security officer or ask to see the Supervisor. Make a note of the precise time, the conveyor belt number and any other information that may be relevant. (This would no doubt only apply in very extreme and rare cases).

As the difficulties that may be encountered arise from ignorance, it may be a good opportunity for the CA to discuss with the Airport Authorities, the need for an understanding of our problems and to include appropriate guidelines to security staff when training or refresher courses take place. It might even be possible for an ostomate(s) to participate in this exercise! In addition, it would appear appropriate for a suitable accommodation to be made available within the proximity of the security area for the purpose of more intimate examinations, if considered necessary, in order to avoid the feeling of being "marched off" to another location. In my two instances it appeared that no specific place had been set aside for this purpose.

Although it may be possible to influence the Security Services at airports in the United Kingdom with regard to this problem, making headway in other countries would no doubt prove more difficult.

Finally, although as ostomates we can be most sensitive to our situation, we must not lose sight of the fact that our safety as flight passengers is paramount and accordingly we should be prepared to deal with all eventualities that we might encounter at each security desk.

Stop press • Stop press • Stop press

A meeting took place between representatives from CA, Monty Taylor (chairman of trustees), Mary Thomas (trustee), and BAA head of security and his assistant at Heathrow Airport on Friday 26th August. BAA and CA are collaborating in the production of a document, "Guidance for passengers travelling with ostomy or similar devices". This document will include information about travelling with medicines and medical equipment, details about what to expect at the airport and tips to speed up your journey through security. It will appear on the BAA website and the CA website and also be published in a future issue of Tidings. CA's offer to provide a training session for those BAA trainers responsible for training security staff is also being considered.

Don't forget your CA Travel Certificate...

Before you go on holiday, obtain a travel certificate from CA and get it signed by your doctor and stamped with the practice stamp.

As you queue up at security, fold the travel certificate open at the page in the language of the country you are in and keep it in your pocket (not your handbag which will be on the conveyor belt!)

Readers' writes

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

Dear Tidings

My stoma is now two and a half years old following an emergency operation at the Conquest Hospital in Hastings where I received the utmost care and attention. Following this I had home visits from my friendly stoma nurse, Sue Field, who gave me assurance and advice on all aspects of this "New Life" I now lead. I have confidence in the fact that she is always willing to offer help and advice should it be needed.

I find Tidings is an excellent magazine and it is so interesting to read of other colostomates' problems and tips on how to lead a normal life. I am now 87 years old and find having a stoma very restrictive after my previous very active lifestyle as regards getting out and about as it so often misbehaves at the wrong time! Thank goodness I am blessed with a great sense of humour!

Yours sincerely
E. H. (Ms)

Dear Friends

A fortnight or so ago I rang CA head office and asked if it was possible to speak to Colin Allum re his article in Tidings. It was so unusual to read about someone with the same cancer as myself. He was on holiday and due to return shortly.

He called on his return and I was able to talk about his op etc., which is still on the cards for me, although I have had a colostomy since February. He patiently answered so many of the questions that were troubling me - no flim-flam - just straightforward answers.
I enclose a donation which is another way of saying thank you both to Colin and to the Association for being there to help me get my head around things.

Yours sincerely
S.I. (Ms)

Dear Editor

With reference to a letter in the Spring 2011 edition of Tidings from Mrs R.T. on the subject of disposal of "bags", I became a colostomate five years ago and at the time was living in a bungalow. Once I had asked the local council how I should dispose of my "bags" they supplied me with large yellow bags into which I put my used closed "bags". The yellow bag was collected on dustbin day and a new bag left.

Three years ago my wife and I moved into a warden controlled flat where I found things more difficult. The rules did not allow me to have a bag outside of the flat and I did not feel that it was very healthy having it in the flat for up to two weeks.

The answer came to me after seeing an article in Tidings. It was for flushable "bags". I sent for a sample of their product and have never looked back since. I just remove the clean outer 'bag' and put that with the normal rubbish together with the wipes I use to clean the stoma. Then I flush the inner bag down the toilet. I find the "bags" extremely easy to use and have never had a leakage.

Yours sincerely
P.M. (Mr)

Dear Tidings

My husband has a colostomy. He has also had a catheter for the last twelve years. I enquired at our local council offices in Witney Oxon to see if they do clinical waste bag collections. They do and you have to arrange this via the district nurse who will tell the council that you need a collection, ours is weekly and very reliable - a new bag is left. It is a private firm working with the council.

Hope this solves the home disposal problem for Mrs R.T. in the spring issue of Tidings and her council has the same system.

Kind Regards
E.H. (Mrs)

Rosemary Replies. Thank you both for your letters. When we received them the editorial team realised that it is some time since we covered this subject in Tidings. So, for the benefit of those who have only recently had their stoma formed, we include an article on the various options for disposing of used ostomy appliances on Page 30.

Dear Editor

I was diagnosed with Crohn's disease in 2003 (I was 53). Five days later I had major surgery and ended up with an ileostomy because I had developed peritonitis. There was no other option and no chance of a reversal so I just got on with life. Four months after the operation I flew to the States with my husband to meet up with our daughter on her way back from Australia and had a wonderful time.

In 2004 I developed a blockage (adhesions this time) so that was major operation No 2. In 2006 I had

Readers' writes

a few problems with the few remaining centimetres of my rectum, namely discharge of mucus which was, more often than not, blood-stained. It also felt very uncomfortable. The crunch came at the very end of our holiday in New Zealand. I suddenly passed quite a lot of blood but I felt fine and reasoned that a little goes a long way. I was anxious but it only happened a few times and we were at the start of our five day journey back to the UK. We really had been in the middle of nowhere.

After speaking with my consultant I elected to have the rest of my rectum removed and get rid of the problem altogether. Surgery was quite complex but I was allowed to go home after a week. Five months later we were flying back to revisit Western Australia.

I do not regret having surgery at all. I have an ileostomy but it's not important to me. It does not dominate my life. I do not have a rectum but so what? I don't wrap myself in cotton wool and neither does my family and friends. I lead a very active life.

My husband died of cancer two years ago, but his courage and dignity have been an example to us all. There is life after an ileostomy. If you have problems, face them, and get help. You are not in this alone. It's just a bag. It's no big deal in the grand scheme of things. I have discovered that there is nothing you cannot do if you put your mind to it and just accept what has happened to you.

Yours sincerely
H.C. (Mrs)

Dear Editor

In the first instance I wish to thank you and your editorial team for an excellent magazine. I had my colostomy two months ago and have had excellent service from my stoma nurse. But there are always questions that you remember five minutes after putting the phone down or, in my case, in the middle of the night.

Two articles in issue 22 stand out for me.

First - Diet - The digestive system, mouth to stoma. I have been told to make a note of which foods suit me and which don't but I was puzzled because I didn't know how long food takes to digest. After reading this article I am much more knowledgeable and consequently more relaxed.

Secondly - Rectal discharge and pain. I had been told about this but hadn't realized that if it was a problem there are things which can be tried to help. My pelvic muscles do not work and I have been incontinent because I had no control over my rectal function. The stoma means that I am no longer incontinent. But the rectal discharge creates the very same problem. Having read your Reader's Replies I had the confidence to talk to my stoma nurse about this and, after consulting my consultant, he has suggested a phosphate enema which has helped and I know can be repeated as and when. I am surprised as you were that more people had not replied but one reason may be that we don't always know which questions to ask and there may be many of us who have been suffering in silence.

Thank you for the help you have given me.

Regards
L.T. (Ms)

Dear Tidings

I recently read your reader's letters about rectal pain after colostomy. I am a 41 year old man and had a colostomy in 2010. The operation and recovery went very well and I had no problems with the stoma. However, because the cancer wasn't diagnosed for six months, it had spread to my liver. So a year after the colostomy operation I had to go in for another operation to cut out 80% of my liver (which has grown back nicely).

After this operation I began to get pain in my rectum. I have seen GPs and stoma nurses who all had never heard of it. Up until I read your readers' letters, I felt so alone.

When I get the pain I have to go and sit on the toilet (because it feels like I need to go) and I get the most painful contractions like the stump is trying to expel something, but there is nothing there. I thought it might be because I have to take slow release morphine for another nerve condition and that can cause constipation. So I started taking Movicol twice a day and sometimes a little Senna once a week in the evenings. I have to say that I wasn't particularly constipated to begin with but one will try anything to stop the pain and contractions.

I am pleased to tell you that so far this regime has worked very well. Now this is just an assumption on my part, but I started the regime because I thought that it might be possible that the brain still believes that the rectum is connected to the bowels. Therefore any problems with the bowels or even slow transit might trigger the brain to produce pain in the rectum because that is where it thinks the problem is. I hope that this information might help one or two of your readers. I don't think one has to make one's movements runny, just soften them up a bit and help the bowels move it through.

Best regards
Dale Kennett

Rosemary Replies: We received a number of responses to the letters on rectal pain we published in the last issue of Tidings. Thank you to everyone who wrote and e-mailed. Unfortunately are not able to include them all. However, a leaflet on this subject will be available soon.

Dear Editor

In answer to Ms J.W. in the summer issue of Tidings: Since having my ileostomy three years ago following ulcerative colitis I have received my supplies from Fittleworth, totally hassle free.

I have also been informed by my doctors that they no longer do third

Readers' writes

party prescriptions so now it's a trip to the doctors to put in my repeat prescription, wait two or three days, back to the doctors to pick up said prescription then post it away to Fittleworth. It is such a hassle now. I found one phone call and a delivery so much easier as I now have to plan for weekends, bank holidays etc to ensure my supplies arrive on time.

J.D. (Ms)

Dear Editor

I too, like Ms J.W., use Charter Healthcare. The only hiccup I had was two years ago at Christmas when because of holiday hours I was asking for supplies for the third time in four weeks and Charter said I must clear it with my surgery. This I did and got my supplies. I find the service impeccable.

When I read some of the stories and letters in Tidings, I realise how lucky I have been. I'm coming up to three years with a colostomy with really no trouble. But then I think that of course most of us are lucky in treatments and outcomes otherwise the magazine would be many times thicker!

Yours gratefully
R.W. (Mr)

Dear Editor

On reading the letter on P41 of Readers' Writes in the summer issue of Tidings magazine I feel very sorry for Ms J.W. It can be a real chore having to deal with orders, collect from one place and post to another etc.

I have been preparing for my summer holiday. Although I have only had an ileostomy since Jan 2011 from rectal cancer I try to circumvent problems before they arise. I advise my surgery, stoma care company and pharmacy by fax of any incoming requests, changes of medication or equipment in advance of it happening. Because of this method everything has run smoothly. Two weeks before I travel everything has arrived as requested and correct. Even the airline was advised of medical equipment and medication, for which they allocated 5kg free of charge (with a letter to prove I have a medical condition).

In this instance if the patient advises the surgery exactly what the prescription is and that it is ongoing until further changes are advised they would surely accept matching script requests from third parties. Should you require a change of quantity or item advise them in advance.

I understand the surgery's reasoning. However, consideration on behalf of a patient like an ostomate who has regular scripts for a medical condition is called for.

Yours sincerely
J.P. (Mr)

Dear Editor

I would like to share with other ostomates the experience of using a new product by ConvaTec, it is called Vitala. It fits around the stoma. The product can be worn for up to 12 hours. The wearing time increases daily. I have worn mine gardening and whilst travelling by train. When I was trying the product I had full support from ConvaTec. I have a hernia around the stoma and it was still suitable. I am very happy with it. Stoma nurses are being trained about the Vitala and it will be available on prescription. Dotty (as my stoma is called) was delighted with it and she looks forward to being undisturbed on our flight abroad very soon.

Yours sincerely,
E. B.

Dear Editor

In issue 22 of Tidings Ms J.W. writes about having to now get the prescription from her doctor then send it to her supplier. This is the way my doctor has worked for eleven years, ever since I had my cancer op. I do have two friends who have been over supplied with pads and pouches when their suppliers have had control. So although it's annoying having to change one's routine I am sure her doctor is correct in saying NHS resources are wasted when suppliers have control.

Kind Regards
Y. B.

Dear Editor

In Readers' writes J.W. (Ms) comments about her supply service and rightly so. I use Fittleworth for mine and nothing could be easier. With each delivery they provide a postage paid reply envelope. When I need supplies I prepare a note for the Surgery listing the items required (it is important to quote the Code for each item) and I attach the postage paid envelope asking that it be used for sending the prescription to Fittleworth. Within 2 or 3 days my needs are delivered to my front door. What could be easier than that?

Best regards
B.S. (Mr)

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

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

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

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

via email:
associate-editor@colostomyassociation.org.uk

or write to:
Associate Editor
Colostomy Association
2 London Court,
East Street,
Reading RG1 4QL

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

Yours
Rosemary Brierley
Associate Editor

98%
AGREE*
“Fits my
body’s
contours”

SenSura® Mio

*Source: Product evaluation results DK, UK, FI, NL, CH. Total respondents: 218

“It has given me the best confidence I could ever ask for”

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Coloplast

Dear Nurse

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

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.

Q: *My wife had an ileostomy operation about three years ago and in that time she has handled everything in a constructive and positive manner. However, since her operation she has developed a problem with bad breath, which is getting worse and starting to affect her confidence, as she is not aware of it until someone tells her. She has asked friends and other people with an ileostomy if they have ever come across this problem and what can be done about it. Although one or two said they had the problem nobody new how to deal with it. Any help regardless how big or small would be most helpful.*

A: I have to admit this is something that I have not come across before. 'Bad breath' is usually due to a gastric (stomach) problem or to diet. It may be worth keeping a food diary to see if the 'bad breath' is due to certain foods. Perhaps a visit to your GP to arrange for some simple tests will help find the cause. I know it must be very difficult to discuss something like this but a simple test may just identify the problem and lead to a cure.

Q: *I have an end stoma and irrigate. I have had my rectum removed but on occasion feel the urge to go to the toilet. Is this normal if I have no rectum?*

A: I have had several patients who have suffered with the same distressing symptom as you even when the rectum has been removed. This can often be explained as 'phantom rectal pain' similar to 'phantom foot pain' when people have had their leg amputated. Most people learn to live with it although many say that it helps psychologically if they sit on the toilet. Although they obviously cannot pass any stool through the rectum they do say that it helps as just the action of sitting on the toilet fools the brain into thinking they have had their bowels opened.

Q: *I have had pain around the stoma for four days and the output is very watery. Can you advise on what may be causing this?*

A: I am unsure as to what could be causing this pain, as it could be one of several things. You do not state if your stoma is an ileostomy or a colostomy. It could be that you have had a blockage due to either a food bolus (if it is an ileostomy) or constipation (if it is a colostomy), which would hopefully settle quite quickly. Or it could be due to a parastomal herniation (a weakness in the abdominal muscle around the stoma causing a swelling and pain). I hope that it has now settled but if not or if it returns I would suggest a review by your stoma care nurse to assess the problem and identify a solution.

Q: *I had my colostomy about 11/12 years ago. For the first 9 years all went relatively well, just usual troubles leakage and soreness now and again. Then, like one or two of your members I began having more discharge from my back passage along with soreness and itching. Then after a while bleeding. My doctor suggested hospital tests and has prescribed Sudocrem and Canesten HC. Tests have found nothing wrong. The Sudocrem has kept the soreness at bay but Canesten HC didn't help at all, still no cure.*

Having been OK for 9 years I couldn't understand what was different, it seems to relate to what I eat. The leaking of fluid became worse in the evening. What was I eating or drinking pm? A coffee at 3pm, main meal at 6pm - no drink – then coffee between 7 and 8pm. So the coffee was changed to tea and within a few days things improved. Do you think instant coffee was causing the problem? If so why would this be?

A: This is a very distressing complaint for many ostomates. Obviously I do not have access to your medical records so do not know the reason for the initial surgery. The discharge is probably mucus and this can cause irritation and soreness. It may be due to inflammation in the defunctioned rectum and this could be helped with creams such as you say you have tried. It may also be why you have found that coffee has made it worse as some patients say caffeine can increase irritation in an inflamed bowel. It may be worth speaking to your GP further to see if a steroid based foam/suppository on a short-term basis would help reduce the inflammation. Alternatively, if it is very distressing, a referral to your local colorectal consultant may be appropriate. The consultant may be able to discuss the potential to remove the rectum completely.

Q: *I wondered if you could offer some advice on Spontaneous Diarrhoea, which I have been suffering with for about 4 or 5 months. Every 4 weeks or so my bag will rapidly fill with solid faeces (a very large amount) and is then followed almost instantly by diarrhoea. It first happened whilst I was changing my bag in a public toilet on a campsite, the diarrhoea occurred while the bag was off, which was very distressing. It's affecting my quality of life. I am confining myself to the house every 4 weeks so it won't happen in public. Can you offer some advice. I had a bowel resection in early 2010 which was when my stoma was created.*

A: I assume that from how you describe the output, you have a colostomy. I assume you have already investigated the possibility that this is related to your diet but if not it may be worth keeping a food diary to see if this is due to a certain food you are eating. Alternatively it could be due to an intermittent obstruction in the bowel, which may need investigating by your consultant to identify the cause. Dependant on the cause the treatment will differ. If no obstruction is found it may be worth trying Fybogel, one sachet twice a day, to help to regulate the output, but I would suggest you see the doctor before trying this.

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 about twice a day.

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

Editors Comment

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

If so write in and tell us:

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

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

Helpful Ostomy Support Groups & Organisations...

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

Stoma Care Open Days…

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

Date: 12th October 2011
Venue: Community Centre, Bell Lane, Kesgrave, Ipswich
Time: 10am - 3pm
Organiser: Ipswich Hospitals NHS

Date: 12th October 2011
Venue: Gretna Hall Hotel, Gretna Green
Time: 10am-3pm
Organiser: Convatec

Date: 13th October 2011
Venue: Charlotte House Hotel, Lincoln
Time: 10am-12noon
Organiser: Hollister

Date: 14th October 2011
Venue: Earl of Doncaster Hotel, Doncaster
Time: 10am-12noon
Organiser: Hollister

Date: 15th October 2011
Venue: Weetwood Hall Conference Centre, Leeds
Time: 10am-3pm
Organiser: Colostomy Association

Date: 19th October 2011
Venue: The Windsor Hotel, Worthing
Time: 11am-3pm
Organiser: Worthing Hospital

Date: 21st October 2011
Venue: Royal York Hotel, Ebor Room, York
Time: 10am-12noon
Organiser: Hollister

Date: 22nd October 2011
Venue: Weetwood Hall Conference Centre, Leeds
Time: 1.30pm-4pm
Organiser: Leeds Hospital

Date: 3rd November 2011
Venue: Broadstreet Rugby Football Club, Binley Woods, Coventry
Time: 11am-3pm
Organiser: University Hospital Coventry and Warwickshire

Date: 12th November 2011
Venue: Health Professional Education Centre, Blackpool Victoria Hospital
Time: 10am-2pm
Organiser: Blackpool Victoria Hospital

Date: 15th November 2011
Venue: Ryelands Clinic, Lancaster
Time: 11am-3pm
Organiser: Morecambe Bay Stoma Care Nurses

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

• • • • • • • • • • • •

SASH

- The Sash belts are available on prescription and suitable for both male and female.
- All belts are custom made from information given on our Order Form and a hole is cut into the belt flange to fit your preferred pouch.
- No fittings are required. Belts are processed and mailed within two working days.
- For further information and to obtain an Order Form Freephone : 0800 389 3111

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

"the ring of confidence"

- This lightweight unobtrusive belt is designed to help eliminate leakage problems by holding the adhesive section of the pouch against the body during all activities.
- The belt also gives added security against the pouch becoming detached and will help to support the weight of a full pouch

Ref. no. SR103

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

Ref. no. S1

Freephone 0800 389 3111
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SASH stoma support and parastomal hernia belts are suitable for Colostomy, Ileostomy, Urostomy, Umbilical and waistline Incisional hernias. The SASH stoma hernia belt has been designed and developed by an ostomist to give support to a hernia that surrounds the stoma without restricting normal body movement or limiting muscle use.

For more information:
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Telephone: 0044 (0) 1702 206502 Fax: 0044 (0) 1702 206502 Freephone: 0800 389 3111
E-mail address: info@sashstomabelts.com Website: www.sashstomabelts.com

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- > **ISO Quality assured service**
- > **Free gift and MRSA resistant flannel with first order**
- > **Complimentary wet or dry wipes & perfumed disposal bags with each order**
- > **Award winning personalised service**
- > **BTEC qualified stoma & continence customer support staff**
- > **Access to stoma care nurses for unbiased product advice and support**
- > **Prescription collection from your GP if required**

Marketplace

advertise...your events • messages • services here...

In touch...with Tidings... The Royal Glamorgan Stoma Care Support Group...

The group was formed in 1998 by people with a colostomy, ileostomy, urostomy together with the Stoma Care Nurses. The aim of the support group is to provide support, guidance and information to new and existing patients and their families, who have a colostomy, ileostomy or urostomy.

How are we organised? We have a small committee who are responsible for the administration of the group and the organisation and running of the social activities.

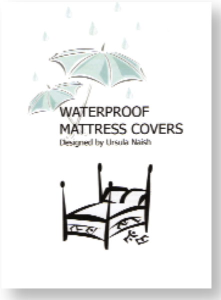
Group Meetings... These take place four times a year:- Two coffee mornings/exhibitions

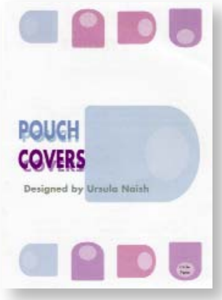
The meetings are held in the Coffee Lounge, Royal Glamorgan Hospital, on a Saturday morning. These mornings enable you and your family to meet other people and view the manufacturer's displays of appliances and accessories in an informal setting. Samples of products can be arranged for you to trial.

Two social events held in June and December:

- Bus trips to encourage confidence to go out socially after surgery.
- Christmas lunch provides an opportunity to enjoy lunch with other people who have similar conditions to yourselves.

For more information...contact:
Domenica Lear - Admin Co-ordinator
Telephone: 01443 443053
Email: Domenica.Lear@wales.nhs.uk





If you have a product to sell, an event to advertise or a message to communicate, you can place a small-ad for as little as £20.

Stoma care nurses... if you would like to promote your Stoma Care Department, its services and events... for FREE...

Then just get in touch... contact:
editor@colostomyassociation.org.uk

colostomy association

Donation Form

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

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

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

We provide:

- **An Outreach Programme** 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 seventy 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) ensures we are able to continue to produce four issues of Tidings per year.
- **Donate via Telephone or online via our Website:** These donations are easy to make...and are secure. Telephone donations are via RBS WorldPay simply call the Colostomy Association office during working hours to donate. To donate online visit: www.colostomyassociation.org.uk
- **Legacy donation - A gift in your will:** If you are about to make a will, or are considering making a change to your current will, please consider leaving a legacy to the Colostomy Association. Your legacy could secure the Association's future and provide continued support to all those 'living with a colostomy' present and in the future.

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

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

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

To donate...Please fill in the form on the next page and return to the address overleaf - thank you

Donation & Standing Order Form
Thank you for your support

colostomy association

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

Note: Please ensure that we have your correct details: full name, address and postal code thank you

My Details: Title: Name: Surname:
Address:
Postcode:
Telephone number: Email:
Optional Information: Date of Birth: Reason for your stoma:
Stoma Type: (Please tick) Colostomy ☐ Ileostomy ☐ Urostomy ☐
(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**
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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:** / / 2011

2 **Single donation:** (a donation of £15 or more covers the production of four issues of Tidings magazine per year)
☐ (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

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☐ 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:** / / 2011

Registered Office: 2 London Court, East Street, Reading RG1 4QL Registered Charity No: 1113471

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

Carole O'Ryan writes about how chronic diverticulitis led her to start...

Oswestry Stoma Support Group

Carole pictured with husband Danny...who has been her rock throughout her illness and fight back to good health.

Carole writes...A colostomy! That happens to other people not me! Here I was 58 years old, married with two sons, three grandchildren and involved in activities ranging from ballroom dancing to volunteer work at Whittington Castle. I had suffered chronic diverticulitis for years, which led to incontinency, and as a result I had to give up work. After serious side effects from medication my doctor referred me to the Royal Shrewsbury Hospital where Mr. Hunt, after a variety of tests, recommended a colostomy but said I must decide.

So, as living with my condition was really miserable I decided to take Mr. Hunt's advice! My husband Danny and I thought it was the only way forward. My husband has been my rock. He has given me strength and support at all times. Following Sister Tracy Lunt's patient pre-op explanation of every detail of the process I had my operation on 7th December 2005. The diverticulitis had caused so much damage it resulted in a major operation plus nine days in hospital, allowing me home just before Christmas. I felt rather uncomfortable but went out to Christmas dinner – remembering this advice from an old friend who had an ileostomy for years - 'It's there for life, accept it, name it and get on with it.' I called 'it' George after a good friend, sadly now deceased, who was very calm but all of a sudden would become very excited.

I tried to get on with life and found it much easier as the pain had gone and I didn't have to keep running to the toilet. It wasn't easy but much better than before. After two months I was dancing, going out and holidaying in Spain. Then I developed a huge parastomal hernia, which was totally unexpected. Other than the stoma care nurses I had no one else to talk to, as there wasn't a local support group. After positive discussions with my consultant, doctor and stoma care nurse I decided to start my own group. At this stage reading 'Tidings' was a great help!

The group formation had to be put on hold as on 20th December 2006 I was back in the Royal Shrewsbury for a hernia repair. This time I didn't go out for Christmas, as it was rather painful. Sadly the hernia came back, which made me even more determined to go ahead with the support group. Once again my plans for the group were thwarted as early in 2008 I was rushed into the Royal Shrewsbury as the hernia had strangulated. I had an emergency operation and my stoma was moved to my right side and renamed George the second!

After a lengthy recovery, with the help of my friends Anne and Dorothy I got on with the task of establishing a stoma support group. Due to its central location I chose the Memorial Hall in Oswestry as our venue. Unfortunately the group formation was again put on hold as a hernia developed on the new stoma. This was very big and so uncomfortable that I found it difficult to walk. After losing 2½ stone in 4 months this hernia was repaired on 9th March 2011 and during this operation my stoma was moved back to my left side so I now had George the third!

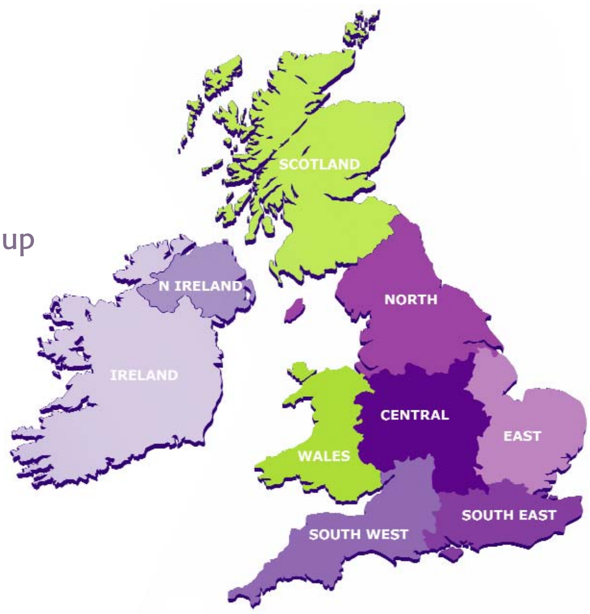
This time there was no stopping me I was going to get started! The hall was booked and leaflets distributed to every surgery, chemist, supermarket, district nurse! The stoma care nurses informed patients and others of our first meeting. Over thirty manufacturers/supply companies were contacted and whilst the response was minimal it was encouraging and helpful.

The inaugural meeting was held on 12th July 2011 at which Maggie from Wilkinsons spoke on the benefits of support garments. At the second meeting held on 9th August 2011 Steve Crane from Trent Direct gave an interesting talk and generously paid for our room hire for two months. SecuriCare Medical is sponsoring the third meeting arranged for 13th September 2011.

So far we have about 14 people attending our meetings. My mother, Dorothy and Anne help at the door and also make the tea and coffee. What I found so wonderful was to see people who did not know each other talking as if they were old friends – this is my aim – for people who are going through the similar experiences to come together and share those experiences with one another.
The group has started well, with meetings set for the second Tuesday in every month and I hope it will flourish. As for me, I'm hernia free and have just started using a new product by ConvaTec called Vitala, which if successful means me becoming bag free for 12 hours a day. Early days, but already I feel I have much more freedom. Through it all the dedicated staff of ward 25 The Royal Shrewsbury Hospital, Tracy Lunt and her stoma care team, Mr. Hunt, and my family doctor have given me time and support.

If you would like to get in touch with the Oswestry Stoma Support Group. Carole can be contacted on 01691 671624 or via e-mail: caroleoryan14@talktalk.net

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



Stoma support groups in your region...

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

Scotland

Midlothian:
GOSH
Contact: Alex Topping 01501 772154
Maggie's Edinburgh Timetable
Contact: 0131 5373131

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

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

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

England - North

Cheshire:
I.C.U.P.S
Contact: Stoma Care Nurse 0151 604 7399
Cestrian Support Group
Contact: David Burgham 01244 310461
Countess of Chester Hospital
Contact: Julie Clements 01244 366170
Drop in Clinic
Contact: Angela Perks/Deborah Singleton 01625 661598
Stockport Support Group
Contact: Angela Simpson 0161 419 5059
TOMAS (The Ostomates of Macclesfield and Surrounding Areas)
Contact: Kath Wood 01625 875442
Warrington Ostomy Support Group
Contact: Jane Shaw 01925 662103

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

County Durham:
South West Durham Ostomy Group
Bishop Auckland
Contact: Betty 01388 814535 Colin 01388 773757 Jen 01325 311266 Maureen 01388 818267

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

Lancashire:
Oldham Stoma Support
Contact: June Wilde 0161 678 7086
Trafford Bowel Care
Contact: Jackie Carey (Secretary) 0161 7489 659 Doreen 0161 9627 818 John 0161 7484 655

Merseyside:
Crosby Support Group
Contact: Barbara Percy 0151 5292842 (Afternoon)
Aintree Stoma Support
Contact: Carmel/Pauline 0151 5292842 (Evening)

Northumberland:
Northumberland Cancer Support
Contact: Pat Fogg 0191 4102679

Teeside:
Bowel Cancer Support (Semi Colon)
Contact: Mr G Dickson 01642 563747 Pat Brydon 01642 897903

Tyneside:
Gateshead Health NHS Trust (Stoma drop in clinic)
Contact: Sister Heather Wilson 0191 487 8989 Ext 2221
NHS Molineaux Centre
Contact: Lesley Brown 0191 219 5656
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: Michelle Speight 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: CA for details 0800 328 4257
Scarborough Stoma Support
Contact: Sister Jean Campbell 01723 342388 Amanda Rowe 01723 342446
The Hull and East Riding Colostomy Support Group
Contact: Pete Smith 07989 565335 and Pete Rennard 01482 793966

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

England - Central

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

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

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

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

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

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

West Midlands:
Colostomy Group
Contact: Diana Wick 0121 4242730
Coventry Stoma Support
Contact: Martin Robbins 02476402616
Newhall Stoma Support Group
Contact: Sarah French 07773 396236 02476402616

England - East

Bedfordshire:
Saturday Social Club
Contact: Karen Richards 01234 792278

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

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

Hertfordshire:
Connect
Contact: Lin Hart 01279505273
Colonise
Contact: Gill 01727 851556
Hertford Stoma Support Group
Contact: Ralda 01992 535311
Stevenage Ostomistics
Contact: Alfred Levy 01767 316958
Stoma Fellowship
Contact: Andrea/Mandy 01438 781133

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

Norfolk:
Ostomy Friendship & Support Group
Contact: 01553 770288/768271/775698
Ostomy Friendship Group of King's Lynn
Contact: CA for details 0800 328 4257
Stars
Contact: Anne Brown 01603 661751

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

England - South East

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

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

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

Kent:
Ashford Stoma Support
Contact: Chairwoman - Mrs Ursula Naish 01233 640863
Atoms Support Group
Contact: Maria Culleton SCN 01227 769679 or 07827997424
Canterbury & Coastal Stoma Support
Contact: Marie Culleton SCN 01227 769679 or 07827997424
Dover & District Stoma Support
Contact: Marie Culleton SCN 01227 769679
Dover Stoma Friends Group Support
Contact: Julie Bell & Ros Marshall 07771345701/01233616646
Maidstone Stoma Support Group
Contact: Judy or Kirsty 01622 224305

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

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

Oxfordshire:
Oxfordshire Ostomy Fellowship
Contact: Pat Longworth 01235 524163

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

Sussex:
(SAS) Brighton & District Stoma Care support
Contact: Sylvia Bottomley 01273 554407
The Ostomy Friends Group
Contact: Jane Quigley 01323 417400 Ext 4552
West Sussex Princess Royal Stoma Support
Contact: Tina Walker 01444 441881 Ext 8318

England - South West

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

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

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

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

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

Wales

Blaenau Gwent Self Help
Contact: Celia McKelvie 01873 852672
Royal Glamorgan Stoma Care Support Group
Contact: Domenica Lear 01443 443053
Swansea Ostomy Self Help Group
Contact: Glynis Jenkins 01792 418245
Wrexham Ostomy Friendship Group
Contact: Mrs R Thomas 01978 359445

Northern Ireland

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

Eire

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

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Reference: 1. Flushability test based on the UK and European standard for domestic waste, Würzburg, Germany.

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