Winter 2010 | Issue 16

colostomy association

# Tidings

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

## inside...

**Welcome to 2010 from our President and Chairman**

**Open Door interview with** Sarah Crane CEO **Pelican Cancer Foundation**

**Colostomy Reversal** readers experiences

**CA Volunteer Bob Buckley writes about Liking Yourself**

**plus...**
- **Readers' stories**
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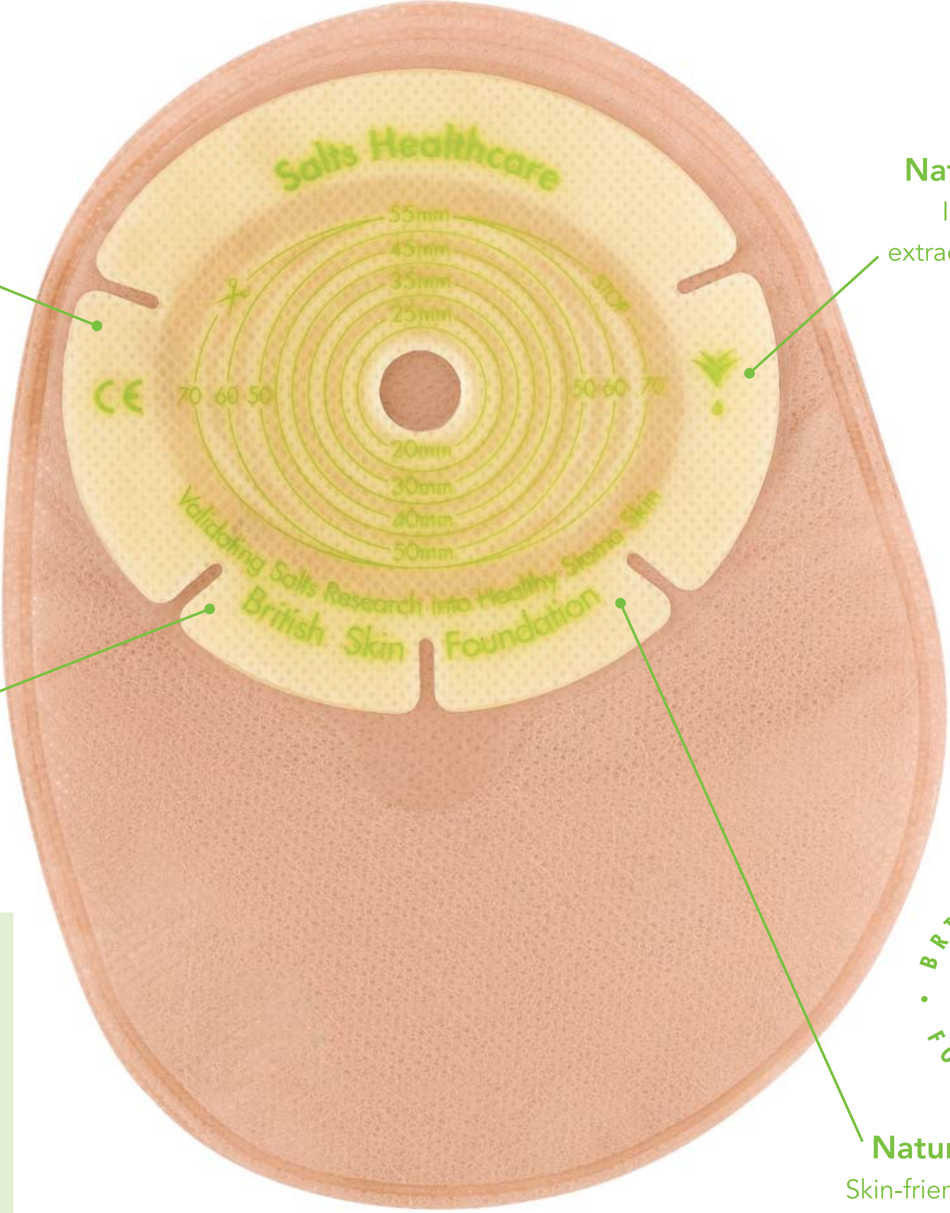
- **Your letters**

**Happy New Year to ALL our readers from the Colostomy Association...**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Validating Salts Research into Healthy Stoma Skin
British Skin Foundation

# welcome to **WINTER**

**Winter is definitely here this year with most of the country covered in a white blanket of frost and snow prior to the Christmas festivities!**

Although snow can be a real nuisance affecting our everyday routine it does bring with it a peace and quiet that permeates our surroundings and stops us in our tracks. I often think how wonderful it would be for the world to stop now and again – so that we could all stand still just for a little while.

The winterbreak offers us time to take stock and think about what we have achieved this year. It gives us time with loved ones and allows us to meet friends old and new. Winter also gives us the opportunity to complete things that we would normally put aside for the pleasure of sitting in the garden on a long warm summers evening. So, it does have its good points!

Looking back over 2009 the Colostomy Association has achieved so much and has really moved forward – well done to everyone!

Here's a reminder of what the CA has achieved in 2009...

CA exhibits at The Association of Coloproctology of Great Britain and Ireland Annual Conference 2009 to raise awareness about the work of the CA to consultants/surgeons. (kind thanks to Coloplast Ltd for sponsoring exhibition graphics)

CA pilots and finalises volunteer training programmes – thanks go to Ernie Hulme, Bob Buckley and Jean Scott and to all those who attended the pilot days and training days. Courses included – Introduction to CA, Telephone helpline with Home and Hospital visiting coming next year. (kind thanks go to Coloplast Ltd, CliniMed/SecuriCare and Salts Healthcare for hosting these events)

CA welcomes two new members to the Board of Trustees – Jackie Dudley and Ann Leppington-Clarke plus a new general manager, Richard Bray who with the help of Mary Thomas and members of the CA complete the CA Strategic Plan.

CA exhibits at World Council of Enterostomal Therapists 2009 (WCET UK) to raise awareness about the work of the CA to Stoma Nurses. (kind thanks go to and CliniMed/SecuriCare for sponsoring this event)

CA is gifted its own stoma care nurse - Amanda Gunning. (kind thanks go to and CliniMed/SecuriCare Medical for sponsoring Amanda)

CA launches its very own ostomate 'Open Day' as part of its programme of reaching out and raising awareness. (kind thanks go to Maureen Kelly-Smith/SecuriCare Medical for helping to make the day a success)

CA website launches online donation (http://www.colostomyassociation.org.uk/donate/donate-online.asp)

CA launches on Facebook (organised by Gill Herbert – CA Office Administrator – nice one Gill!) and joins Just Giving.

So as you can see we have achieved much and with a New Year just beginning who knows what will be achieved in 2010!

It has been a pleasure and a privilege to edit and contribute to Tidings this year. I would like to take this opportunity to thank the members of the Editorial Team for their enthusiasm, support, suggestions and articles. I would also like to thank all the advertisers for their ongoing commitment. And to thank all those working in the background who help with production, print and mailing. But most importantly I would like to say a BIG thank you to all our readers and to those of you who emailed and sent letters and contributed articles without your continued support Tidings magazine would not be possible!

**Tidings** has grown as a magazine and is warmly received by ALL who read it – as I always say **YOU make Tidings what it is...YOUR magazine!**

Jane

editor@colostomyassociation.org.uk

## An inspiration...Brave colostomate Willo 'comes out' as a plinther in Trafalgar Square...as part of the One & Other live artwork 2009 by Anthony Gormley

One & Other was a live artwork by sculptor Antony Gormley, which took place over 100 days during the summer of 2009. No fewer than 2,400 people from as far afield as the Shetland Islands and Penzance occupied the plinth for sixty minutes each, picked at random from nearly 35,000 who applied.

Willo who is a colostomate, artist and sculptor and has been in a past issue of Tidings, was picked to appear on the plinth in Trafalgar Square. Willo thought the project would be an amazing forum to raise the profile of the groups and charities she supports.

"As a long-term survivor of various forms of cancer (including secondary bone cancer) I thought I might be able to promote Christie Hospital, where I received most of my treatments over several years. I hoped also to raise awareness for other charities I support the Colostomy Association, Scope, YMCA, the Big Issue, NSPCC, Childline, British Heart Foundation (my partner having died suddenly of heart related illness on New Years Day 2007). Also, Leukaemia Research (my 'ex'-nephew died of leukaemia at the age of 14 and I have a friend currently undergoing treatment) plus various third world charities as awell as a local Aids/HIV support group".

**Thank you - Willo you are an inspiration. You can see Willo on her plinth at: www.oneandother.co.uk/participants/Willo**

**Kind thanks to all who have contributed to this issue of Tidings.**

# inside

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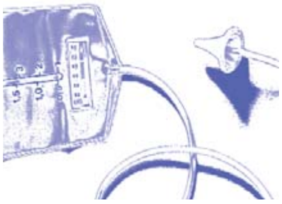

**Tidings** is YOUR Magazine...

**Editorial Submissions:**
We welcome your contributions to Tidings - 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

## 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.

The Colostomy Association is a charitable company limited by guarantee (Registered Charity No: 1113471).

### How to get to in touch...

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

By telephone:
**General Enquires:** 0118 939 1537

Stoma care queries only:
**Helpline:** 0800 328 4257

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

Find us on Facebook:

Find us on Facebook

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

Simply visit our **website** and **register** at:
**www.colostomyassociation.org.uk**
or contact
**General Enquires:**
0118 939 1537 for more information

**Tidings Magazine Spring Edition advert booking by 18th January copy by 8th March publication April 2010**

## 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.**
**www.colostomyassociation.org.uk**

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

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Payment methods accepted for your donation

story please get in touch. Tidings is also interested in commissioning articles please contact the Editor.

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.

**Supply of 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 2480 pixels x 1772 pixels at 300 pixels per inch (equal to 21cm x 15cm).
- File sizes not less than 10Mbytes uncompressed
- Images compressed in JPEG format.
- For scanned images please set at 300 ppi in RGB mode and scan original @100%.

**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 contact the Editor

**Write to:**
**Colostomy Association**
2 London Court
East Street Reading
Berkshire RG1 4QL

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

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

**Advertising Enquiries**
For advertising enquiries and media pack
**Tel: 0118 983 6226**

# welcome from our PRESIDENT

When I accepted the honour of being your President I determined to tackle two issues which seem to me as a surgeon to need very special attention. All human beings are so vulnerable and generally much more private than they may appear – people with stomas are especially vulnerable and often especially private too.

Regrettably it must be admitted that surgeons are all too often remote and inaccessible – frequently failing to afford the details of colostomy construction and management, the attention to detail and importance the patient so richly deserves. There is little doubt that imperfectly constructed stomas and parastomal hernias are far more common than they should be.

We must all thank heaven for the wonderful people, mostly women from the ranks of the nursing profession, who have chosen to specialise in colorectal nursing and stoma therapy.

It is one of my priorities for the Association to enlist their support in making all permanent colostomates aware of the irrigation option for managing their stoma.  As many of you know irrigation is far more widely practiced in the United States than in the UK, and I was surprised to discover that my own first cousin had had a colostomy for a whole year before being offered the irrigation option. In his own words his life was “transformed” after he had been taught the technique and his recent Christmas card reaffirmed his willingness to help make this option available to others.

It is of course presumptuous for your President to imply for a moment that any one method is superior to another, but it does seem fundamental that each person should be made fully aware of what is on offer. All of the offices in the Association are “onside” with this initiative, and I was thrilled to meet Mandy Gunning (the Association’s stoma care nurse) whose infectious enthusiasm for this project is a positive inspiration.

It is my sincere hope that we will in the next few weeks put together an action plan which will mean that no one in the future will repeat the experience of my cousin. Furthermore patients who have not been irrigating but who would like to take a second look at this option will, through the good offices of the Association be able to have “a real second look” – with time to talk and learn.

One further longer-term objective that I personally, as a surgeon, would like the Association to address relates to the availability of specialist units around the country to address any problems of stoma revision as they arise. It takes a particular surgeon with a fastidious personality to achieve the attention to detail that is necessary to achieve the perfectly optimal stoma that each person deserves. I have already approached the Association of Coloproctology, of which I was once the President, and have received a positive and encouraging reply. I hope I will be able to report some progress to you in a future edition of Tidings.

During 2009 I have operated by invitation with camera relay to other surgeons in Moscow, St Petersburg, Romania, Sweden, Germany, France, Italy and South Korea. Whilst 2010 continues to look busy I do promise you all that I will try to help your organisation to help you in the various ways that you may need.

I know that every one of you would wish to send condolences to Anne Leppington-Clarke on the recent loss of her husband Terry and sympathy and love in her own current illness which is keeping her off of work at this time. Sue, Mandy and I will stay in touch with her and discuss the planning and detail of the irrigation initiative so we do not lose the benefit of her unique experience while she is undergoing treatment. Throughout my working life she has been an inspiration to my patients, my colleagues and myself – we wish her a speedy recovery.

**I wish you all a Happy New Year!**

**Professor Bill Heald OBE**
**President**

# welcome from our CHAIRMAN

2009 was a year of progress and we go optimistically into 2010 with plans to further promote the work of the Colostomy Association and support for our members. Although the credit crunch has been on all our minds, last January the Trustees were initially pessimistic as everyone started to economise but, I am delighted to say, this has not entirely proved to be the case as we have been particularly fortunate in receiving several legacies during the year.

Tidings Magazine is now such a well-respected Journal within the stoma field for which Jane Wood, our editor, deserves great credit. She has spent many hours interviewing ostomates and stoma care professionals and liaising with manufacturers and suppliers. This has resulted in a quality publication and increased advertising revenue, and we are very proud of the result. On the minus side, with a growing charity, costs have increased substantially and as we rely on the generosity of our members I hope you will feel, if you can afford to do so, that you will continue your financial support, as this is vital for the role we envisage for the care of existing and future colostomates.

In 2010 we intend to concentrate on further improvements to our new website; this is proving to be an area where real progress is being made and the number of "hits" we receive from abroad, particularly the USA, has increased substantially. Whilst many of us with young grandchildren will appreciate that they are far more adept at "surfing the web" than we are, I never cease to be amazed at the number of "silver surfers" who now use on-line banking and shop via the Internet. For this reason we have recently set up a secure "donate online" area on our web site which is proving to be very popular especially with the decline in the use of cheques and cash.

As members of the Colostomy Association, Tidings is YOUR magazine and YOUR input is a vital link with us and other ostomates. Our editor and Trustees want you all to know that we actively encourage articles of interest for publication whether amusing, informative or even constructive criticism. We are planning a page entitled "my most embarrassing or amusing stoma experience" and welcome your submissions as I am sure we can all recall at least one! A £20 M&S voucher will be presented to the best submission and the editor's decision will be final.

**A Happy New Year to you all!**

**Monty Taylor**
**Chairman of Trustees**

# pelican cancer foundation
## opens its doors to Tidings
### **advancing surgery** through **education and research**

Sarah Crane – Chief Executive
Pelican Cancer Foundation

Tidings visits the **Pelican Cancer Foundation**...to learn more about the work of the Foundation from **Chief Executive Sarah Crane**

**Pelican Cancer Foundation is celebrating its tenth anniversary in 2010. Pelican stands for Pelvic Liver Cancer and we sponsor medical research and medical education to advance precision surgery for rectal, liver, prostate and bladder cancer. The charity was formed as an independent organisation working at a national level to improve the survival and quality of life for patients with these cancers.**

**The charity is deeply involved with the work of Professor Bill Heald and colleagues at Basingstoke and North Hampshire Hospital who have achieved so much to improve the outcomes for patients with rectal cancer (bowel cancer that occurs low in the body), due to their development of Total Mesorectal Excision (TME). TME is a precise surgical treatment for rectal cancer: the traditional surgical technique was relatively crude but Professor Heald discovered that his meticulous dissection of the anatomy when removing a tumour in the rectum provided better outcomes for patients in terms of surviving longer and with a better quality of life after surgery. This meant patients had fewer complications after surgery, especially in terms of sexual and urinary problems. It is true that this advance in surgical practice is claimed to be one of the major contributors to improvements in cancer survival statistics in the last 20 years.**

**Today the aims of the charity remain sponsorship of medical research and medical education that can advance precision surgery and contribute to patient survival and especially better quality of life following treatment for rectal, liver, prostate and bladder cancer.**

## Pelican Cancer Foundation

The charity is based in The Ark, an exceptional building situated near the hospital in Basingstoke. The Ark was built with charitable funds in 2003 and Pelican is fortunate enough to have 50% of the first floor of the building. We have research offices, charity offices and a teaching suite that can seat up to 50 trainees. This allows us to carry out much of the charity's activity right here – research fellows have exceptional office space and we can run a variety of courses for multi disciplinary professionals throughout the year.

We have surgeons and members of the multi disciplinary cancer teams coming to Pelican for courses in a wide variety of topics to do with cancer surgery. Whenever appropriate live surgery from the operating theatre is transmitted into the Pelican lecture room so that the surgeons can share their expertise in "real" time with the audience. Two-way audio visual links allow the audience to ask questions and discuss the various problems as they arise. Pelican was one of the first centres to create this link with high definition technology for both laparoscopic and open surgery.

PELICAN
cancer foundation

**If you would like to find out more about Pelican Cancer Foundation visit: www.pelicancancer.org**

## Editors Comment

Many thanks to
Sarah Crane - Chief Executive
Pelican Cancer Foundation
who took time out of
her busy work schedule
to meet Tidings and
contribute this article

> **"Surgeons at Pelican are all proficient laparoscopic surgeons but they believe that the decision whether to carry out open or laparoscopic surgery has to be taken in the best interest of each patient".**

Laparoscopic "keyhole" surgery is being undertaken more frequently and every 6 months Pelican organises Clinical Immersion Courses for 8 surgeons to spend 4 days to have hands-on experience under the watchful eye of their mentors and colleagues. An invaluable though somewhat daunting experience! There is a strong Government initiative for all colorectal patients to be offered the option of minimally invasive laparoscopic surgery by October 2010. Pelican is one of 11 centres around England that is helping surgeons to develop the necessary skills for this target.

The surgeons at Pelican are all proficient laparoscopic surgeons but they believe that the decision whether to carry out open or laparoscopic surgery has to be taken in the best interest of each patient.

## Department of Health support

The most extensive project was sponsored by the Department of Health to provide a National Training Programme for colorectal cancer teams in the TME surgical technique and procedure. This project followed on from a series of pilot courses sponsored by Macmillan Cancer Support for colorectal surgeons in the Trent Region. It proved so successful that the Cancer Tsar, Professor Sir Mike Richards, agreed that these courses should be supported by the Department of Health and be made available to all colorectal multi-disciplinary teams throughout the country. This project was completed in 2007 since when we have continued to run a wide curriculum of courses and meetings.

## What is a **multi-disciplinary team?**

A multi-disciplinary team is made up of a group of clinicians: surgeon, physician, nurse, radiologist, pathologist and oncologist who are all involved together in a patient's treatment.

> **"Bowel cancer has this particular potential for surgeons and radiotherapists and chemotherapists to co-operate in a constructive way in optimising outcomes, reducing the side-effects, the things that make people miserable and unhappy, and at the same time to get cured of their cancer." (Bill Heald)**

PELICAN
*cancer foundation*

The benefit of Pelican for patients is the improved cancer survival statistics that TME, improved techniques in liver surgery, precise treatments for prostate cancer and awareness of bladder cancer provides. In the early days of the charity we offered a referral service for rectal cancer patients but, once we had completed the National Training Programme and TME had become the "gold standard" treatment offered in almost every hospital in England, we found that this became unnecessary. These days if patients do get in touch with us we can refer them either to one of the cancer advice charities or

The contribution of Pelican and the associated surgeons cannot be over stated. Their work has made life saving changes to thousands of patients all over the world. Today the life expectancy and quality of life for many bowel cancer patients is far greater than it was just ten years ago thanks to their innovative work.

recommend they ask GPs for a referral directly to an appropriate colorectal surgeon. We always greatly appreciate it when patients get in touch with us and value their feedback but we do not offer any specific advice or support.

## Medical Research

People often ask why there are so many cancer charities and what is different about them. We believe that Pelican is a unique organisation supporting the advancement of surgery through education and research. We bring together different research groups to support multi disciplinary (e.g. radiology, surgery, oncology and pathology) in many different centres around the world. All our research must be clinical with the objective of improving patient quality of life and survival by advancing precision surgery. It is well documented that surgery cures more patients of cancer than any other treatment but the research investment in this area in minuscule – 1.3% of the national research budget.

At present Pelican has **four main areas of research interest** within the pelvis

- **Low rectal cancer**
- **Prostate cancer**
- **Bladder cancer**
- **Liver cancer** (colorectal metastases/secondaries)

**Low rectal cancer** is an extremely complex disease, found in a part of the body particularly difficult for the surgeon to reach – especially in men, who are more likely to have a narrow pelvis. There are currently three accepted surgical treatments for this cancer and our research is to investigate the outcomes of these surgical options. Pelican is strives to improve patient quality of life following surgery.

The **3 accepted surgical treatments** are:-

**1. Low anterior resection (LAR) –** is a challenging operation to carry out but if done well it has low rates of recurrence and the patient can avoid a permanent stoma. However functional outcome is difficult to predict.

**2. Standard APE –** (the technique gradually being phased out) is a challenging technique with higher recurrence rate than LAR or elAPE and sphincter function cannot be restored and so results in a permanent stoma.

**3. Extralevator APE (elAPE) –** a large amount of tissue is removed (the bowel sphincter complex and levator muscle removed en bloc) resulting in a permanent stoma. elAPE has markedly reduced recurrence and tumour perforation rates compared to standard APE.

## Impact of Pelican Cancer Foundation

It is difficult to estimate the exact benefit of our work for patients since it is supporting surgeons and other members of the MDT but over the last ten years 5000 individuals have benefited from development training at the Pelican Cancer Foundation. If each individual takes away something from our courses that can help a cancer sufferer to live longer and with a better quality of life then we are achieving our mission. Too many patients with cancer in the pelvic region still have disappointing outcomes from surgery in terms of sexual and urinary function but we believe that good quality research and education can make a real difference.

Thousands of patients have been recruited into clinical trials supported by Pelican, looking at a variety of different issues within the pelvic region. The most obvious impact has been the introduction of MRI for all rectal cancer patients before surgery following the MERCURY research study. An exciting area of ongoing work where results are just about to be published is on treatment for prostate cancer – once again looking at ways to treat patients in the most precise way to improve survival and their quality of life.

It must be fair to say that for a small organisation Pelican has flown high. Our mission remains to help today's patients have an improved chance of survival and good quality of life after treatment.

**If you would like to find out more about Pelican Cancer Foundation visit: www.pelicancancer.org**

### Editors Comment

If you would like to be
featured in our Open Door Series
please contact us
e-mail:
editor@colostomyassociation.org.uk
or write to:
Colostomy Association
2 London Court East Street
Reading RG1 4QL
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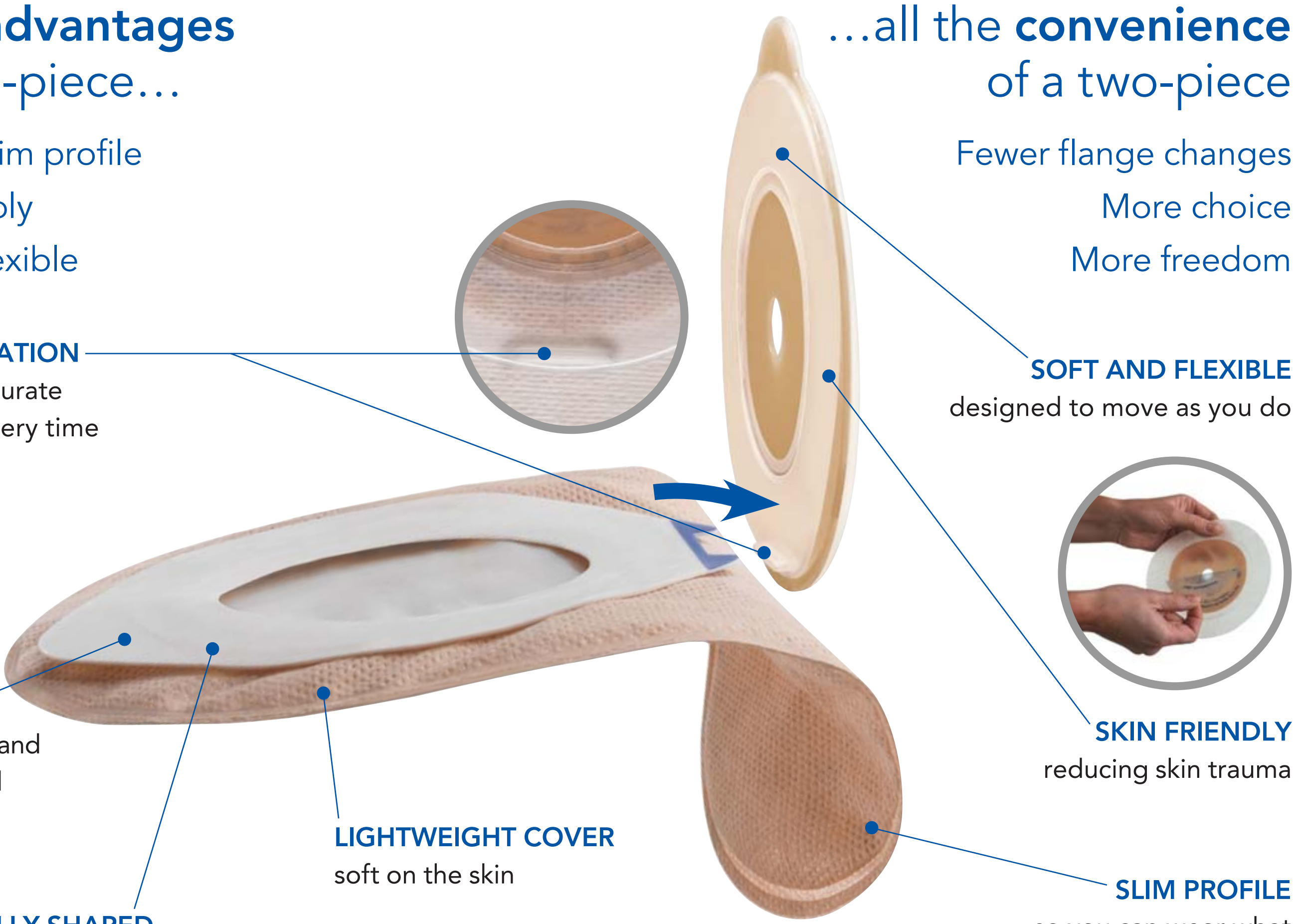

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# Update on new stoma care products and services

**Tidings** is always **interested to learn about new stoma care products and services**...from colostomates, 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.**

## B. Braun Medical Emerald...Prescription Delivery Service

Emerald is the Prescription Delivery Service from B. Braun Medical delivering a full range of Ostomy supplies to customer homes, within the UK

- 24/48 hour delivery
- Your choice of complementary washbag
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- Customised cutting service
- Discreet packaging
- Special delivery instructions to suit your lifestyle

**To discuss the service offered by Emerald contact our friendly and experienced customer care team... on freephone: 0800 163 007 or email: info@bbraun-emerald.co.uk For more information about B. Braun Medical and Emerald visit: www.bbraun-emerald.co.uk**

## Hollister launches NEW QuietWear pouch...

Hollister are pleased to launch our new QuietWear pouch incorporating the AF300 filter, available on prescription from November 2009. This exclusive technology will allow you to go about your daily activities with renewed confidence and comfort. This new pouch can truly address the pouch noise concerns of Ostomates and with its cloth-like material provides a comfortable feeling. **Contact Hollister Customer Services on 0800 521 377 for more details and to request a sample.**

## Salts Healthcare NEW Confidence Natural... One-Piece Closed Pouches

Salts Healthcare are pleased to announce the launch of Confidence Natural, a new range of one-piece closed pouches, featuring the exciting new Flexifit™ wafer, infused with Aloe Vera extracts. The unique five-sided shape of the Flexifit™ wafer provides more flexibility and security as it fits more closely with your body's natural contours, reducing leaks and increasing comfort. Extracts of Aloe Vera, a plant well known for its skin soothing properties, have been added to the hydrocolloid wafer which is soft against the skin and may help to protect the delicate area around your stoma.

Confidence® Natural WITH ALOE EXTRACTS

**For free samples of Confidence Natural, which is available in large, standard and mini, please call Freephone 0800 626 388.**

## Opus Healthcare DeoGel – Deodourising and Lubricating Spray

DeoGel - is especially designed to deodorise pouch odour and reduce pancaking - a handy sachet is available. The deodorant is formulated to breakdown odours rather than mask them with another scent, the lubricant reduces static and thus the likelihood of the plastic sides of the pouch sticking together. Available on prescription and can be obtained from your usual supplier.

**Samples are available and can be requested by visiting www.opus-healthcare.co.uk or by calling 0800 458 7605**

## Ileomate... NEW from Peak Medical

Peak Medical is pleased to announce the launch of the **new EuroTec 1 and 2 piece drainable pouches** with **SoftSafe** closure and **Finger Pocket,** now available on FP10 prescription. The **Ileomate 1 piece and Combimate 2 piece drainable pouches** incorporate a **unique Finger Pocket** for the insertion of one or two fingers to enable easy drainage and hygienic cleaning of the pouch. **A 24-hour high capacity bar filter** with a Gore-Tex membrane protects the filter from 'strike through' caused by liquid stool. An additional safeguard is a layer of film, the 'raincoat' which separates the filter from the stoma. **For more information please see Peak Medical's advert on page 41. To be one of the first to try the new Ileomate and Combimate range of drainable pouches simply call the Peak Medical Freephone number 0800 652 0424.**


Peri-Prep Sensitive
No-Sting Protective Film
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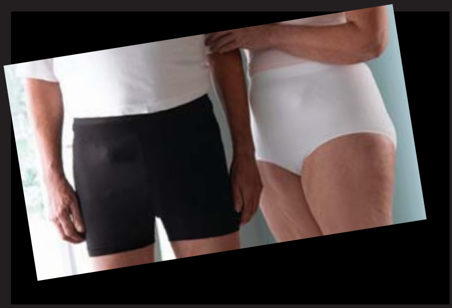
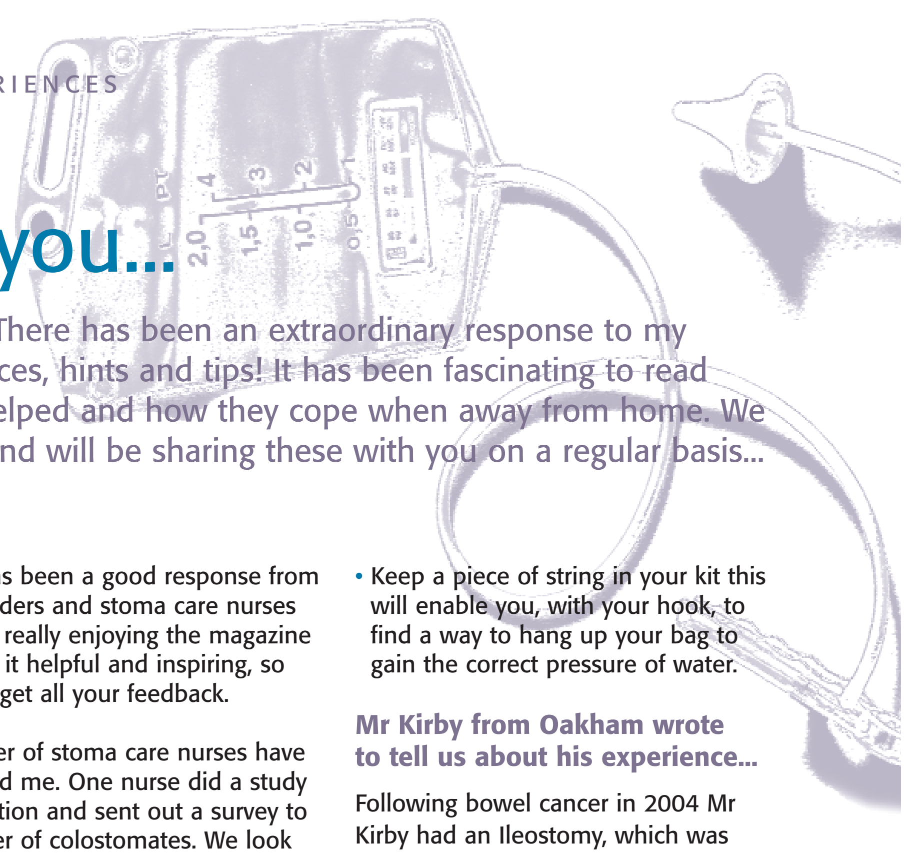
Product Code: WA1
SALTS



# Irrigation and you...



Sue Hatton Executive Trustee writes...There has been an extraordinary response to my request to Irrigators for their experiences, hints and tips! It has been fascinating to read how others irrigate, how they were helped and how they cope when away from home. We have had some wonderful accounts and will be sharing these with you on a regular basis...

Many thanks to all who wrote in saying they were glad to see a regular page for irrigators. Please keep your contributions coming they are very interesting and may encourage stoma care nurses to promote irrigation and colostomates to try irrigation.

We would like stories from both sides, from colostomates who have found irrigating easy and from those of you who have been upset and disappointed that it did not suit you because it was uncomfortable or impractical.

Please use this page as an irrigator's discussion platform, somewhere to swap ideas and hopefully give encouragement to others who may be contemplating asking their stoma care nurse if they are able to irrigate.

There has been a good response from both readers and stoma care nurses who are really enjoying the magazine and find it helpful and inspiring, so good to get all your feedback.

A number of stoma care nurses have contacted me. One nurse did a study on Irrigation and sent out a survey to a number of colostomates. We look forward to hearing the results of this survey. Another nurse invited me to her hospital to talk to some of her patients about irrigation. These are such positive steps, if only more stoma care nurses would use our group of willing volunteers who irrigate, it would be a great way of getting more people irrigating.

### Ann Curruthers, from Southampton wrote in after receiving the Autumn Issue of Tidings with her irrigation experiences...

Ann says, "At first, I irrigated every other day and it took between one and a half hours and two hours. Then, I found after a few months that I was able to put in more water (6 litres) and only needed to irrigate every third day. Now, the procedure only takes me an hour. I sit on a comfortable stool in the bathroom, use a butcher's hook to hang up the irrigating bag and enjoy listening to the radio or CDs for my hour of sitting down".

### Ann's hints and tips...

- Never attempt to get up and answer the phone whilst irrigating. Take the phone in with you if possible.

- When travelling, always use bottled water, especially in hot countries.

- It is best to pack your irrigating kit in your hand luggage but beware if using a metal butcher's hook with sharp ends, as you will probably have to open up the whole kit.

- Keep a piece of string in your kit this will enable you, with your hook, to find a way to hang up your bag to gain the correct pressure of water.

### Mr Kirby from Oakham wrote to tell us about his experience...

Following bowel cancer in 2004 Mr Kirby had an Ileostomy, which was reversed the same year. Twelve months later the cancer returned. He then had to have a colostomy and chemo.

He was first introduced to Irrigation during an Open Day in Leicester. After talking to a CA representative about irrigation he followed up the conversation and contacted his stoma care nurse to find out if he was a suitable candidate for irrigation. He found he was! Here are his comments…"it is AMAZING 24hours trouble free, no anxiety and a feeling of well being I haven't felt for years!"

Mr Kirby has written to his surgeon telling him of his success suggesting that he should encourage irrigation where possible.

"The NHS gave me a 'new life' and I will always be grateful. Thinking back to those dark days following major surgery and thirty weeks of chemo, I was in no condition to take on board the benefits of irrigation. There are also the stoma care nurses to be considered coping with growing numbers of people needing their expertise. It is inevitable that the attitude of 'if it isn't broke – don't fix it' or 'he's coping with his bag so leave him alone' could prevail."

### Mr Kirby ends his letter with...

"Sue Hatton is right to focus on the possibilities of bowel irrigation. The difficulty will be maintaining that focus with the array of equipment and commercial pressure".

## Douglas Haywood, former physical training corporal in the RAF wrote a very heartfelt letter to Tidings...

Douglas started to irrigate six months after his surgery in 1994 at the age of 61 following bowel cancer.

"Irrigation enabled me to lead a normal lifestyle and I found instant peace of mind with all the bag problems completely eliminated. For 14 years, without any success, I have desperately tried to bring this bowel management method to the attention of colostomy patients who may be able to use this system so that they too can benefit from irrigation."

Douglas comments "Please thank Sue Hatton for giving hope to Irrigators like me, by helping to raise awareness about Irrigation. I hope more colostomates will get the message to sample and experience this simple body cleansing method that is second to none. If only we could get a higher percentage of irrigators like the States (50%) compared with the UK (5%), stoma nurses would experience far less stressful days and have more time to inform colostomy patients that there is an alternative for some – irrigation.

## Tidings invites you...

Do you have something to share about irrigation? We would like to invite those of you who irrigate or teach irrigation to edit the Irrigation pages in Tidings.

We are grateful to Sonia Woolven for her previous contributions.

Any readers, stoma care nurses or CA volunteers who would be interested please email:-
editor@colostomyassociation.org.uk

## We look forward to hearing from you...

**NB. From B Braun** - Thank you for featuring our Irrimatic Pump product in your Irrigation and you section of the Autumn Tidings magazine. Unfortunately Sue Hatton penned a response to Dorothy from Nottingham that says B Braun offer a free trial via the stoma care nurse. Unfortunately this information is not correct. Those interested in a trial have to pay for the pump (£260.64) but are offered a money back guarantee if they return the pump within 30 days. Free trials are not available from the stoma nurse.

## Irrigation - you and your routine...what do you do whilst irrigating?

Whilst irrigating one day, Sue Hatton passed the time wondering what other people do - here are a few answers from fellow irrigators including Sue's…

Sue Hatton, Executive Trustee and CA volunteer - listens to Terry Wogan, puts in 4 pints of water, takes 20 mins, does her make up routine, reads magazines and answers the phone - not all at the same time!

Bob Buckley - CA volunteer, says he reads the paper or a good book or does the crossword. Time goes much faster then.

Paul Foulger - CA volunteer, times his irrigation to coincide with a good TV programme and sometimes takes a portable TV into the bathroom with him!

**Tidings would love to hear more!**

## Irrigation - a few hints and tips...

- Use 2 suction hooks, one may come off the wall.
- Use kitchen roll to dry the equipment when you are cleaning up.
- Practice deep breathing before you start, if you are relaxed it helps the water go in better.
- Take a spare kit with you when you are away from home, e.g. holiday. The kit takes up very little room and you may spring a leak on the existing kit!
- If you are new to irrigation, be patient it may take some months to perfect your technique. Don't give up it'll come.
- Use bottled water when you are away, even in the UK water in a different part of the country may affect you differently to your own tap.

## Irrigation... Freedom and control

In general, irrigation is a safe and effective method for achieving a continent bowel. Irrigation can give the colostomate a new sense of freedom and control.

Irrigation needs to be discussed with and taught by a stoma care nurse, and the procedure should be followed. It is not a technique which suits everybody, although for colostomates who suffer persistent problems with their colostomy it may be an appropriate option.

### Who cannot Irrigate?

- People with complications such as a prolapse, stenosis or large hernia.
- Those with further bowel disease e.g. Crohn's disease or diverticulitis.
- Irrigation may not be successful for those suffering from persistent diarrhoea.
- Young children who have difficulty sitting still for the required time. As with all teaching of young children, if the child is old enough to take an interest in the working of the stoma, it may be possible to overcome this difficulty by making a game of it: "Let's see how long you can go without needing a bag".
- People with renal or cardiac problems. Irrigation could cause fluid overload, or slow the heart rate excessively by stimulating the vagus nerve.

## 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
e-mail:
editor@colostomyassociation.org.uk
or write to:
Colostomy Association
2 London Court East Street
Reading RG1 4QL
or telephone:
0118 939 1537

# Building on success... new for 2010 - Open days

## • Reaching out
## • Building awareness
## • Moving forward

The Colostomy Association will be organising two Open Days in 2010 building on the success of the pilot Open Day held last September in Swansea. The first of these events will take place in the Plymouth area in May. We are currently in talks with China Fleet Country Club where we hope this event will be held. The Club is one of the West Country's best-kept secrets and is just 10 minutes away from Plymouth city centre. China Fleet Country Club offers extensive leisure and sporting facilities and boasts glorious views over the River Tamar. The second Open Day will take place later in the year in Glasgow and venue, dates and information will be announced in a future issue of Tidings Magazine.

The Colostomy Association has decided that Open Day events are more beneficial to ostomates and that events such as these will replace the National Conference. By holding Open Days we can reach out to even more ostomates, their families and carers.

We will be inviting stoma care professionals from the local and regional hospitals to get involved and join us on the day. Also, both patient associations IA and UA will be invited to come along and local support groups will be most welcome. Stoma care industry representatives will be in attendance to answer product queries and exhibit the latest stoma care products and accessories.

Those attending these Open Days will gain increased knowledge about their stoma via workshops and talks on the day. Learn more about stoma care and have time to discuss problems or issues that affect them via questions from the floor or if more appropriate in person with our stoma care nurse.

These two events will build on the success of the last event and are part of the Associations continued development programme. The aim being to reach out and support ostomates in different parts of the UK and in doing so build awareness for the Colostomy Association.

### Plymouth Open Day

**Date:** TBA May 2010
**Time:** 10:30pm - 2:30pm

**Venue:** China Fleet Country Club
Saltash, Nr Plymouth, Cornwall
www.china-fleet.co.uk

### Proposed Event Agenda

- Registration
- Welcome
  Talk about the CA raising awareness
- Introduction of mini workshops
  Patient story/Hernias/Stoma Care Overview/Irrigation.
- Patient Story – Duncan Wells
  Sharp Scratch (appeared in Tidings Magazine Issue 12)
- Hernias
- Stoma Care Overview – Amanda Gunning and Wendy Osbourne
- Irrigation
- Lynn's Bowel Campaign Workshop
  Siobhan Crowther and Caroline Meakes
- Exhibitors stands will be available throughout the event and refreshments will be available on the day.

If you live in either of these areas or surrounding counties and are part of a stoma support group or run a group please pass the word that we welcome all ostomates, their families and/or carers to our events. If you would like to attend either event to support the Association you are more than welcome. We are encouraging advanced registrations for the Plymouth Event - so if you want to ensure your place please fill in the advanced registration form below and return to the Colostomy Association. We will be sending invitations to our supporters living in the appropriate postcode areas nearer the date. So do please keep a look out for them!

### Plymouth Open Day Advanced Registration Form

**Please complete this form to ensure your place/s at the above event and return by post to:-**

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

**or telephone: 0118 939 1537**
**or e-mail:**
richard.bray@colostomyassociation.org.uk

**Name:** ____________________

**Address:** ____________________

____________________

**Postcode:** ____________________

**Tel:** ____________________

**Email:** ____________________

**No. of places req'd:** ____________________

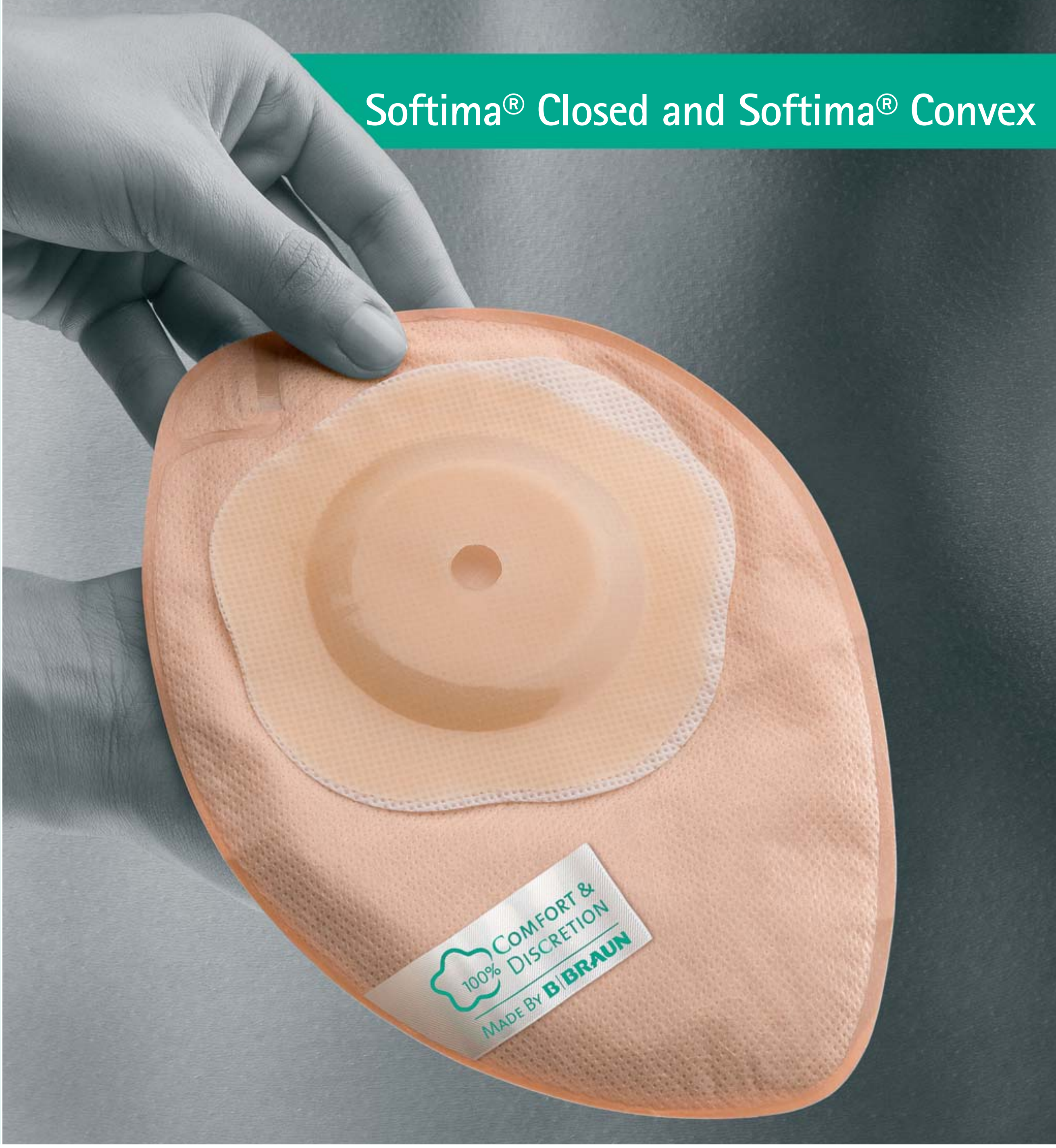
____________________

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

**You will be sent an invitation giving further information about the Open Day nearer the date - thank you.**

## Editors Comment

If you would like more information or would like to speak to someone about these forthcoming events contact:
Richard Bray General Manager
telephone: 0118 939 1537
or email:
richard.bray@colostomyassociation.org.uk
or write to: Colostomy Association,
2 London Court, East Street,
Reading RG1 4QL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# Pathways to a colostomy

## Emergency Surgery - a readers' experience

For some people the first time they hear the word stoma is when they wake up from an emergency operation and find a bag attached to their abdomen.

There has often been no time for a stoma care nurse to prepare them for surgery which may have a profound effect on both lifestyle and self esteem. Neither has there been time to arrange for the stoma to be sited in the most convenient position.

**Saturday April 19th 2008…the date I could now never forget. The date when my whole life changed.**

The day started alright: up at six, out and about driving for a few hours returning home at about twelve-thirty in the afternoon. Nothing unusual had happened. I hadn't driven hard, I wasn't stressed, hadn't lifted or carried anything heavy: just a normal day. Then I started: sweating and sweating. The sweat just ran down my face. I felt my shirt become wet, then the severe stomach pains. My immediate thought was that I had caught a twenty-four hour "tummy bug" so I went to lie down. I was by now in agony. I shouted for my wife, she looked at me and went straight to telephone the doctor.

The pain became more severe and as we waited for the doctor to ring back I noticed that my stomach had swelled up around the navel. When the call came I was given an appointment at the surgery three miles away. In the consulting room as I lay down on the couch I heard a loud pop and the pain eased a little. The doctor said I was too ill to treat and wrote a letter for me to take to hospital and telephoned to say I was coming in.

Reader PANEL contributor

At A&E the triage nurse said, 'You're too ill for me.' She assisted me into a wheelchair and pushed me through to a cubicle where the doctor examined me and gave me an injection of morphine. They passed a tube up my nose and down my throat into my stomach. I kept thinking, what a lot of trouble for a stomach bug. By now though the morphine was beginning to kick in and I must have fallen asleep.

I woke up on the ward. My hands and feet had become icy cold and I began to shiver even though I was covered in blankets. The surgeon then came to the end of the bed and began to explain what was happening to me, but I was closing my eyes and missing a lot of what he said, although my wife heard it all. I did, however, pick up a few odd words: bowel, hernia, strangled, operation, but not necessarily in that order. I still felt I was going colder and started to say as much to my wife and then I heard someone say, 'He's shutting down.'

I remember a man dressed in green wheeling the bed down the corridor, my wife walking along beside me.

Someone introduced himself as the anaesthetist and placed a mask over my mouth and nose. 'See you later,' he said

While all this was going on my wife and mother-in-law were shown into a side room. A doctor came to explain that I might not survive the operation because I was in such a bad way. Later he returned to say that I was through the operation, but the next twenty-four hours was the critical period.

I awoke in a darkened room, two nurses and loads of monitors by my side, tubes protruding from both arms, a clip connected to a wire on my right forefinger, an oxygen mask on my face and the bed felt as if it was rolling under me – I was in the Intensive Care Unit.

The surgeon came to see me on Sunday morning and began to explain how the operation had gone. It appears that it wasn't a tummy bug. In fact my bowel had strangulated and burst – the popping sound in the doctor's – and my stomach cavity was filled with excrement. Initially he only gave me a 20% chance of survival and explained that under the circumstances he put a stoma in place after cleaning out my insides…but I was still very poorly.

It was Monday afternoon before I picked up the courage to look under the bedclothes and see the latest addition to my body: a clear coloured pouch full of air. On Tuesday morning my daily water allowance was upped to 90ml and on Wednesday the doctor said I could go onto a light diet: soup and ice cream. In the afternoon I was told I was too fit to be in intensive care and transferred to a ward.

Thursday was fun: it was when everyone came to visit. First it was the doctor, then the surgeon, the pharmacist, the nurse to take blood, the dietician, the stoma nurse, the newspaper girl and the ward clerk. I was getting exhausted. In fact I must have dozed off and as I woke there was a nurse at the end of the bed reviewing my notes. I said, 'What do you do, please?' 'I'm the pain nurse,' came the reply. 'Oh it's alright,' I said. 'I've already got some.'

Friday morning it was time to sit in a chair at the side of the bed. On Saturday the catheter came out and so did the epidural. On Monday I was taken, propped up by two nurses, to the bathroom for a wash. The pouch at this time was still being emptied by the nurses. This was also the day I decided to go onto coffee instead of the black tea I had been drinking. Four cups later the pouch came off with a vengeance. No matter what the nurses did, another pouch wouldn't stick and if it did, it didn't stick for long. But eventually we got there and I vowed not to have coffee again and to this day I haven't!

Wednesday morning arrived and so did the stoma nurse. Off to the bathroom we went and I did my first pouch transplant. I thought I had done alright until it came off as I walked back to my bed. Second attempt held but I had forgotten to seal the flap at the bottom. I've not forgot since!

Wednesday also saw my daily visit from my surgeon, but with a difference: he began, 'How's my star patient?' which somewhat took me aback. He then informed me that if I continued to make progress I could leave on Saturday morning. After he'd left I asked the ward sister about the star patient bit and she said that not many people had survived what I had gone through – at that point it hit home how poorly I'd been.

Now more than a year later the only problems I have are waking at different times of the night to empty the pouch and where my pouch is located. As my operation was performed as an emergency there was no time for a specialist nurse to mark the ideal spot for a stoma. Consequently my trouser waistline and belt goes right across the middle of the pouch only allowing a quarter of the pouch to operate. This problem was solved by leaving the pouch on the outside of my trousers and buying bigger shirts to cover it. However, the bag capacity gets even less when I have to put my seatbelt on in the car as the lap part of the seatbelt crosses in a higher place than my belt.

**Having a stoma is my big secret. A secret kept from everyone except my wife, two sons, sister and mother-in-law - even my mother doesn't know. I told my wife after the operation that she could tell everyone what was wrong with me but not what they did to me. It's not that I'm scared to tell anyone, it's that I want to be treated normally, no "stepping on eggshells" around me. I want to prove that even with a stoma you can lead a normal life and do what everyone else does.**

**For ostomates whose stoma is situated at waist level, high-waisted trousers can be a solution.**

The following **retail outlets** may be able to help:-

- **High and Mighty**
  Customer Service Team
  0845 601 0212
  (Mon-Fri 9am-5pm)
  www.highandmighty.co.uk
- **Chums (catalogue company)**
  For more information phone
  0871 911 0601 or visit
  www.chums.co.uk

The following **specialist ostomy suppliers** may be also able to help:-

- **Ostomart**
  To request a catalogue
  phone 0800 220 300 or visit
  www.ostomart.co.uk
- **White Rose Collection**
  To request 'Just Men'
  phone 01202 854 634 or visit
  www.whiterosecollection.com

**For ostomates who find that car seat-belts are a problem, devices which reduce the tension without affecting the operation of the seat-belt are available.**

Stocklists are available online just search for 'Carpoint Seat Belt Stopper' or visit...

- **www.care4car.com**
  or Telephone 0845 225 2848
  Carpoint Seat Belt Stopper Klunk
  Klip 2/Seat Belt Comfort Clip

## Editors Comment

If you would like share your experiences with the editor please e-mail:
editor@colostomyassociation.org.uk
or write to:
Colostomy Association
2 London Court East Street
Reading RG1 4QL
or email:
cass@colostomyassociation.org.uk
or telephone:
0118 939 1537

breakaway
*putting smiles on young faces*

## Editors Comment

Many thanks to
Karin and Josh Hicks
for sharing their
experiences with Tidings

# Chronic Inflammatory Bowel Disease – how do you prepare your child and yourself for surgery and the consequences of a life with a bag?

Our son was referred to paediatric gastroenterology in December 2005 when he was diagnosed with ulcerative colitis. Unfortunately he did not respond to treatment and in September 2006 we were told that if treatment remained unsuccessful we may have to face the possibility of surgery to remove the colon.

As a parent you want your child to be whole – the prospect of him having such drastic surgery is of great concern and caused us to investigate the issue in depth on the internet and in libraries (I think I must have spent in excess of 300 hours on the computer and in books). We soon found that there had not been any ground-breaking new developments with regards to chronic inflammatory bowel disease for the last 20 or so years and that none of the "alternative" methods we found out about was suitable for our son as they were only suitable for light/moderate illness and had not been tested properly for side-effects. Therefore they contained a certain element of incalculable risks, which were simply not worth trading this illness in for.

In the beginning we considered the implications of such life-changing surgery to be quite negative, as it would affect our son's health for the rest of his life. Gratefully he was looked after by excellent doctors who were extremely positive and encouraging emphasising that he could lead a (more or less) normal life with little or no limitations; he would reach his full potential and would not need any further medication. Therefore the side-effects would no longer be an issue.

Once we had come to terms with the fact that surgery was a necessity we were able to take a step back and look at it from different angles. We had a lot of talks with doctors and specialist nurses, who explained in depth all the procedures and what was to be expected after surgery. Stoma nurses explained the practicalities of bags and related issues.

Yet all of this information is theoretical knowledge and reality hits home cruelly and with a thump immediately after surgery when pain-relief has to be addressed etc. It is important to be reassuring and supportive, switching one's own emotions off in order for the offspring to be able to deal with the situation themselves. Constant encouragement that things have got to get worse in order to get better is required, and one has to find the inner strength for two to deal with this matter.

We would have liked to speak to some parents with first-hand experience but unfortunately we were unsuccessful in linking up with anyone in the short time that was left to us, as things got worse in January 2007 when the choice was taken out of our hands as our son took a turn for the worse and started losing weight rapidly. Surgery in the end was carried out in February 2007.

The acceptance of the need of surgery is the first step in dealing with this issue. Once that has taken place the head is clear for further investigation and mental preparation. The whole issue "starts in the head" and when medical needs dictate it mind must come over feelings. It is important to get support from specialists who, when you ask, can answer all your questions and provide invaluable help in getting to terms with everything. However, it is equally as important to get support for the time after the operation to help you through the ups and downs of "life with a bag", and who can point out issues that may arise of which you would otherwise be unaware. This is specifically important for parents caring for their children, as children may not always tell them exactly how they are coping for fear of upsetting them when mum and dad had already been so supportive. Therefore "Get Help!" – There is no need to struggle on your own.

## What life is like living with a bag as a teenager...

I spent ages trying to think of an opening sentence. I guess that with the many different openings I could have used to describe life with a stoma, none could quite do it justice.

Life with a stoma is pretty similar to the life of James Bond or playing Poker, it's always unpredictable. If you play your cards right life with a stoma is AOK and you realise how lucky you are that you managed to escape the clutches of death and so on. On the other hand if things go badly the world seems to be against you it can be quite hellish. Leakages, loud farts, rumbling, gurgling, smelly poo, even smellier poo and soup poo are cards that can be dealt!

I have had to learn to readjust my lifestyle in many ways to be able to manage my toilet situation. I carry a bag around with a change of clothes and spare bags etc., for emergencies as well as Imodium for dire situations. In addition to this OUST! has become my new best friend, especially when I'm out and about.

I guess that for a long time I struggled to talk to new people due to having a bag whilst being a teenager. As if being a teenager isn't hard enough as it is! In reality the bag hasn't affected my social life and I still find myself meeting new people and making new friends. People seem to be a lot more considerate than you might think.

Another persistent issue is food. At the beginning I found myself being very cautious but the longer you have a stoma the more you realise that there are very little limitations as to what you can and cannot eat. I still enjoy the occasional Snickers bar and a handful of popcorn. Just remember to chew well and that whatever we eat each one of us is different!

There's so much more I could write...Don't let the above be a deterrent though, just remember - like anything in life there are ups and downs.

**Want to bring your family to Breakaway? Worried about the cost? DON'T! There is help!**

Breakaway exists to support young people with bladder and/or bowel diversions/dysfunctions and their families. No one should miss out on the opportunity to attend a Breakaway event due to financial constraints.

Breakaway receives sponsorship and donations from stoma care companies, fund-raising and private donations. Every penny raised goes directly to the families supported.

Families can apply to Breakaway for funding support. Breakaway cannot guarantee to help every family who applies to the fund but we are passionate that no one should miss out due to limited finances.

**Upcoming events - 2010-2 weekends at YHA National Forest May 28th and August 27th for 3 nights.** The cost of three nights full board accommodation and activities is just £155 per person. Activities may include climbing, high ropes, zip wire, canoeing and much much more!

**To learn more about Breakaway...**
**contact Rachel on 0775 1560013**
**or Julie on 07939 690311**
**or send an email to:**
**break.away@tiscali.co.uk or**
**visit: www.breakaway-visit.co.uk**
**for details of all Breakaway's news and events.**

# breakaways'...Xmas Party

Gill Herbert from CA joins Breakaways' Xmas Party festivities!

I was honoured and privileged to be invited to the Breakaway Christmas Party 2009 which was held at YHA, Derbyshire 27th – 29th November the 4th such event since Breakaway began.

Rachel Clarkson and Julie Bastin, Co-Founders of Breakaway work extremely hard for the charity and this year's Christmas Party event reflected their enthusiasm! The weekend itinerary was packed with exciting activities including tobogganing and snow tubing, a fine Christmas dinner and Saturday night disco all topped off by a visit to Santa and his reindeer via the Santa Express!

Sitting on the outside looking in was an experience I will never ever forget! My visit was both touching and amusing. I saw one parent offering another parent a pouch to try on her 3 year old and a stoma care nurse snow tubing which is another story! (For those of you who have never heard of snow tubing, it's really quite simple: take one rubber ring to the top of a slope, sit in it and slide to the bottom.)

As parents we want all to go well for our children, but what happens when health problems arise? To be told a child needs a stoma can be devastating for both the child and its' parents. Some parents may feel alone with no-one around them able to give the specialist support and understanding they require. Equally a child may close themselves off from those around them or be too scared to join in everyday activities or want to go on school trips. For families of children with bowel and bladder disorders the answer is Breakaway! At Breakaway both parents and children can find the support they need, but perhaps more importantly, they can find themselves, be themselves and have lots of fun along the way!

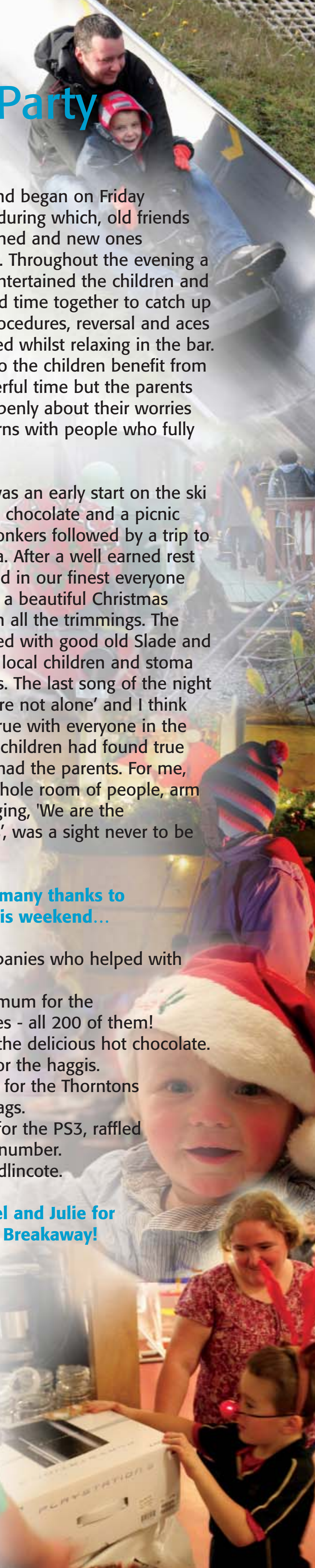
My weekend began on Friday afternoon during which, old friends are welcomed and new ones introduced. Throughout the evening a pet farm entertained the children and parents had time together to catch up on new procedures, reversal and aces all discussed whilst relaxing in the bar. Not only do the children benefit from this wonderful time but the parents can chat openly about their worries and concerns with people who fully empathise.

Saturday was an early start on the ski slopes, hot chocolate and a picnic lunch at Conkers followed by a trip to meet Santa. After a well earned rest and dressed in our finest everyone met up for a beautiful Christmas dinner with all the trimmings. The disco started with good old Slade and welcomed local children and stoma care nurses. The last song of the night was 'You are not alone' and I think that rang true with everyone in the room. The children had found true friends as had the parents. For me, seeing a whole room of people, arm in arm singing, 'We are the champions', was a sight never to be forgotten!

**There are many thanks to give for this weekend…**

- The companies who helped with funding.
- Wayne's mum for the mince pies - all 200 of them!
- Trudi for the delicious hot chocolate.
- Pauline for the haggis.
- Coloplast for the Thorntons goodie bags.
- Hollister for the PS3, raffled by room number.
- YHA Swadlincote.

**And Rachel and Julie for setting up Breakaway!**



# Forty Years On...

**Michael Rose** looks back to when he first had his stoma and recalls his time as a voluntary visitor for the **Colostomy Welfare Group** (the predecessor of the Colostomy Association)

I had my colostomy in Edgware hospital in September 1969, over forty years ago. For over a year I'd lived with a misdiagnosis of piles, but in the end I arrived at outpatients, just after we'd moved house. Things moved fast, so fast I found myself with a bed in what was then termed a geriatric ward in the far reaches of the hospital. I never even saw a surgical ward until after the operation a few days later!

However, I do remember vividly the day before the op. I didn't really know what the operation entailed, not even what it was called. Suddenly, in the late afternoon, an elderly lady arrived and chatted about the forthcoming operation. Suitably shaken, when she realised that I didn't know what she was talking about, she left. Shortly afterwards a team arrived at my bedside and they explained what was going to happen. I had been aware that it was serious but…they left me reeling from the news and Emily Brain, the new General Secretary of the Colostomy Welfare Group (CWG) – for that is who my visitor was – returned and stayed for a while. I am sure, however, that she realised that a proper pre-op visit was out of the question. Fortunately the surgeon, Mr Ryall, also a CWG Trustee, had talked to my wife.

After a five week stay in hospital and a period of convalescence I returned to work as a college lecturer in Willesden. Later I visited the CWG headquarters in Eccleston Square and met some of the newly formed team. The CWG had only come into existence two years previously in 1967.

Emily and my surgeon encouraged me to become a visitor which I was until the early 1980s in the North West area of London. I still have a copy of the first Visitor's manual; there were then only three Area Officers – Western; North Western; and Midlands. The whole of the South East was covered by Emily, her head office staff and volunteers, though that did change during the seventies. Visiting was very rewarding even though I had to fit it in with my work. I had given my colostomy a name – Henry – and made sure all my close friends knew of him. In fact Henry had a moment of fame as I joined an evening class on writing where we were challenged to get into print. I succeeded with an article called "He's always by my side" (about Henry) for which the Nursing Mirror paid me the princely sum of £15!

I was then working and living in Edgware and St Albans. In 1980 I moved to a senior management post in Southall, near London Heathrow and I found myself leaving home before 7am and getting back near 7pm. Two or three times a week I was up at 5.30am irrigating. The surgeon's recommendation to irrigate was the best advice I ever had. It allowed me to get on with the world of work without a major constraint. The job did however force me to give up visiting. There just wasn't time if we were going to have weekends.

All this seems long in the past. I retired because of reorganisation and for the past fifteen years have done voluntary work in my home town – helping witnesses in the Crown Court: working as a guide in the cathedral and as a lay member of Chapter and as an advisor on voluntary work in the local CVS office. I normally irrigate every two days.

Friends and family occasionally ask how Henry is, but for the most part it feels as though he's not around very often. I'd be useless as a visitor now: I'm too far away from the coalface where there are people called stoma nurses. But there is a salutary story for me – one of my visits was to a very elderly lady in Watford who'd been irrigating since the Second World War. The equipment – glass containers and perished rubber tubing – would have been better suited to a medical museum, or probably the dustbin. Sadly it was too late for real change as she was in poor health. So that's why I keep an eye on Tidings to read about new ideas/equipment and what stoma nurses have to say. And I was much cheered to see all the articles on irrigation.

I know I have been fortunate so far with a supportive wife, family and friends and I've been able to travel all over the globe. I was lucky to be in at the start of the Colostomy Welfare Group and to have been encouraged by Emily Brain and my surgeon into taking a positive attitude towards life with Henry. He might have had a few tantrums over the years but my wife says I've caused them – and I don't deserve any sympathy.

**Do you have a story to tell or memories you'd like to share? Email: editor@colostomyassociation.org.uk**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**Clive Blanchard** - stoma support group organiser
**M.E.S.S (Mid Essex Stoma Support)** writes about...

## Editors Comment

Many thanks to
Clive Blanchard
for sharing this article
with Tidings

# Department of Health Consultation Relating to Provision of Stoma Appliances and Services...

On 1st April the Department of Health published the Summary of Responses to the consultation paper launched on 9th June 2008.

With that document, they published an overview of the new arrangements relating to the provision of stoma and urology appliances and related services.

Before considering the content of those documents, it's worth reviewing how we got to where we are today.

### Introduction

In October 2005 the DoH published their first and original consultation document, inviting comments from the Ostomy industry, NHS, patients and all other interested parties regarding their proposals to change the way in which manufacturers and suppliers are reimbursed by the DoH for supplying appliances (pouches etc), accessories and services to ostomates. The proposals within that original consultation were seen by everyone as radical, indeed unrealistic because the proposals seemed to be a simple cost-cutting exercise, without due consideration for the impact of those cuts on everyone involved - from the manufacturers, suppliers, NHS, Specialist Stoma Care Nursing provision and thus most importantly of course, us patients.

### What Happened Next

The action taken by MESS in January 2006 (and subsequently) reflected action taken by the national support groups (Ileostomy Association, Colostomy Association and Urostomy Association). We lobbied all the MPs in Essex, David Cameron and Andrew Lansley (Shadow Secretary of State for Health) requesting their support in rejecting the proposals as unrealistic, unfair and prejudicial to our continued quality of care and thus, quality of life as an ostomate. We wrote to the DoH, the Secretary of State for Health and her underlings explaining in the strongest possible terms, why the proposals were unacceptable. Finally we wrote to our members with a standard letter for them to send to your constituency MP.

More widely, manufacturers and suppliers, led by their Trade Association the BHTA, enlisted the support of individual clients (ostomate patients) and presented the DoH with thousands of letters explaining the need to retain the essential choice of product, services and access to specialist stoma care nursing. Consultants and Stoma Care Nurses also made their views known in letters to the DoH.

We received good support from the majority of our MPs in Essex and also from Bob Marshall-Andrews MP, a Labour back-bencher with whom we discussed everything in a meeting at Homestyle Positive's Rochester office. Further, two Early Day Motions were tabled in Parliament which supported our case, in total receiving the support of over 200 MP signatories.

The responses the DoH received forced them to conduct further discussions and consultations with all interested parties. Since the original consultation back in October 2005, the DoH has maintained a formal and informal dialogue with manufacturers, suppliers and the national support groups. Several, further consultation papers have been published and each time the responses have led to the publication of the next consultation paper - in fact the consultation paper launched on 9th June 2008 was the seventh!

### Department of Health's Objectives

The DoH stated a number of objectives behind the consultations, including to:

- maintain and where possible improve quality of care for patients and provide a consistent level of care
- ensure transparency between what is reimbursed (by the DoH) to industry for services (e.g. appliance cutting and home delivery) and products supplied such as our appliances

- ensure equitable payment to Dispense Appliance Contractors (DACs), such as Homestyle Positive and Fittleworth who operate a prescription management and home delivery service and Pharmacy Contractors (ie High St pharmacies)
- secure value for money for the NHS, whilst ensuring reasonable returns for manufacturers (e.g. the likes of Dansac, Hollister, Coloplast etc) and Dispense Appliance Contractors (DACs), such as Homestyle Positive and Fittleworth who operate a prescription management and home delivery service.

Within the June 2008 Consultation document the DoH listed key services and specifications, with the prices they proposed to pay. They also detailed the level of reduction, which they intended should be imposed upon the reimbursement/payment levels they have been making. Throughout the consultation period that level of reduction in reimbursement gradually reduced from 12.5% to roughly 2% - so it's easy to identify that the DoH eventually began to listen to everyone's concerns regarding DoH's unrealistic demands. In simple monetary terms it means the DoH are more likely to make savings of £5M pa, rather than the £25M pa.

## Responses to the June 2008 Consultation

A total of 85 formal responses were made between publication and the closing date in September. In addition an unstated number of letters and emails were sent directly to the DoH by ostomates, carers and MPs on behalf of their constituents.

Overall, those who responded accepted that the DoH had listened to concerns regarding the importance of maintaining quality of care and choice of appliances and services; further, the proposals were more affordable to the ostomy industry. Nevertheless, many operators within the industry raised a number of concerns relating to annual price reviews, the level of some service fees and compliance mechanisms. They also sought to remind the DoH that while these consultations have been in progress and pending implementation of new arrangements and reimbursement levels, there has been a total freeze on annual reimbursement/payment increases. This means that while raw materials, employment, manufacturing, distribution and research and development costs have all risen, income has remained at 2005 levels.

## The New Arrangements

After three and a half years of discussion, debate and seven consultations the DoH has concluded the exercise subject to amendment regulations being laid down and amendment directions being made in Parliament. The new arrangements will be implemented in April 2010.

I have already touched on the level of reimbursements to industry for supply of appliances and other products and services - overall there will be a reduction of 2% which is a more sustainable figure for industry and the companies operating within it.

## How will it affect us?

In reality it is highly unlikely we'll notice any change. The onus has been placed upon industry to change the way it conducts certain aspects of its business and the new arrangements seek to ensure that everyone works within the same clinical governance framework and offers the same levels of service.

The services they provide are now split into two categories:

**Essential services** - include repeat prescriptions, provision of appropriate advice, home delivery if requested by the ostomate/patient and a supply of wipes and disposal bags.

**Advanced services** - include appliance customisation (i.e. cutting appliances to our size) and Appliance Use Reviews (AUR). The AUR must be conducted by a specialist nurse working on behalf of the DAC or PC or by a pharmacist in the home of the patient or at the supplier's premises, where there must be a specially designated area for confidential consultation. These specialists, if they carry out AURs, must maintain close contact with the NHS healthcare professional looking after the user. DACs (e.g. Homestyle/Fittleworth) and PCs (e.g. Boots) can opt to offer, Essential Services or Essential plus either or both of the Advanced Services.

## Conclusion and comment

For the DoH - there is no doubt that those involved had no understanding of the stoma industry and everyone involved in it, be they manufacturers, DACs, Stoma Care Nurses or patients. That ignorance contributed to the protracted consultation process, as did the continual changes in the Health Department with a succession of changes in Ministerial positions. Nevertheless, the DoH has certainly achieved one of its objectives - to cut costs - although the 2% annual savings could be swallowed up by the High Street pharmacies, which may make the services they provide more widely available.

The DoH's costs of employing management consultants to advise upon and conduct the consultations are estimated at somewhere between £3.5M and £4M - which will, of course, be met by the taxpayer.

Industry - after three and a half years will doubtless be relieved the consultation process is complete, allowing them to again place 100% focus on meeting ostomates' needs. They'll certainly be happier with the final outcome than if the 2005 proposals had been adopted. Larger companies with robust business models will manage the changes more easily than the smaller, independent DACs. These smaller, independent companies are however, now feeling more optimistic as to the future, with the new arrangements confirming the important role they play in the ostomy industry.

Patients/ostomates are unlikely to see any tangible change. Reductions in payments by the DoH to industry should not adversely impact upon areas such as product availability, research and development and the ongoing support of the Stoma Care Nurse population and national and local support groups - all of which are very important because they directly or indirectly impact upon us.

So there we have it; whilst industry will continue to lobby the DoH to 'tweak' the final arrangements before they come into effect in April, everyone who has actively opposed the DoH’s proposals will feel all the time, effort and expense incurred over three and a half years has been well worthwhile. ■

# Gill Herbert launches CA on Facebook -
# What is Facebook and how can it benefit the ostomate?

Well, what is Facebook all about? If you're like me with teenagers and young adults still at home you will probably already have heard the word 'Facebook' in conversation. "I'm going on Facebook Mum, OK". I usually say "Yes, all right", without really knowing what it is or why it interests young people so much. It was only when my daughter went to University last year that I decided to give it a whirl as I had a vague idea that I could somehow communicate with her.

One evening I decided to find Facebook on the Internet. I typed in Facebook in the Google search panel and hit return. I was presented with a home page that said, "Facebook helps you connect and share with the people in your life". That was it, I decided to join there and then. I could be close to my daughter even though she was living in another part of the UK! I found by joining this community I became closer to many more people, my son, my nieces and even long lost friends I had given up on years ago! The power of Facebook is infinite and cannot be underestimated yet how did it all come about!

Well…it's back to the student, University and Internet thing – a potent mix I hear you say! Try to imagine that you are a new student at college in America. The usual way of meeting people is via a publication that colleges pass out to new students at the beginning of the academic year. The idea being to help students get to know one another better. The publication, "yes, you've guessed it," - 'Facebook'.

Mark Zuckerberg (founder and CEO of Facebook), a computer science student at Harvard University decided to create an electronic Facebook, which, he launched from his dorm-room for the purposes of social networking within Harvard. Naturally, its popularity increased and word spread to other American Universities, mostly due to social contact with Harvard. Eventually Facebook began to be used all over the United States and the world and was no longer confined to those in university. People of all ages above 13 years began to use it. As of today, over 350 million people currently use Facebook.

Facebook is a social network service, which focuses on building online communities of people who share interests and/or activities, or who are interested in exploring the interests and activities of others. Most social network services are web based and provide a variety of ways for users to interact, such as e-mail and instant messaging services.

As I mentioned earlier I found that Facebook brought me closer to my family and friends and I think the emphasis on 'closer' is an important one. In fact, closeness is something, which we all need to hold onto in this fast moving world. Facebook offers us a docking point somewhere where we can drop anchor. A place where we can find like-minded people who are interested in what we are all about. That statement really says it all!

Gill Herbert who is a caring person and stalwart supporter of the Colostomy Association - who also has young people still living at home and has had similar 'Facebook' experiences to my own - suddenly thought how good it would be to set up a Colostomy Association Facebook group.

A place where colostomates could meet, share experiences, swop ideas and makes friends. So with her daughter Nicola's help they set about registering the Colostomy Association on Facebook! When all was done Gill emailed all the CA volunteers to let them know about the Facebook group, there was a good response and several volunteers have been very proactive members. The group now has over 130 members.

Online communities can make such a difference to ostomates. Gill points out "Facebook is another way the CA can help the ostomate by providing a space where ostomates can share discussions, swop ideas and talk about issues that really matter to them." Gill also says "Facebook gives the CA an amazing opportunity to learn what issues really affect ostomates". The benefits to the ostomate and to the CA are immense. Gill keeps Facebook open on her desktop all day and if she feels she can help someone she will!

The Colostomy Association Facebook Group offers discussion boards and recent topics relevant to 'living with a stoma' have been:-

- Toilets
- The non-attractiveness of stoma bags
- Reversal
- Liking yourself
- Irrigation
- Top tips
- Tidings Magazine

The Colostomy Association welcomes all ostomates to their Facebook group. Sometimes it is easier to put our feelings into words. Facebook offers this benefit to the ostomate and if they choose to they can hide their personal identity.

Online communities as we have seen in previous Tidings articles offer the ostomate a safe haven where they can be themselves with others who understand them.

### To get you started follow these simple instructions…

Start at the homepage - http://www.facebook.com you will see a screen that asks you to login or sign up for a free account. Click the 'sign up' button, this will take you to a form, fill in your full name, your current status, email address, a password and your birthday. You'll also have to type in a series of letters and numbers for a security check as well as tick a box saying that you understand and agree to the terms of use and privacy policy. Click the 'Sign up now' button when you have completed the form.

A confirmation email will then be sent to your inbox. When you get the email, click on the link in the email to confirm your Facebook account registration. You will then be logged into Facebook. Each time you log on you will be taken to your home page. In the top right hand search box type colostomy association. You will then be taken to the Colostomy Association Facebook Group where you will be asked if you would like to 'join this group.' Click to confirm, you can then add posts, comment to others and join in discussions.

### Editors Comment

Well done to Gill and Nicola!

If you would like to learn more about the Colostomy Association Facebook Group contact Gill Herbert on 0118 939 1537 or email: cass@colostomyassociation.org.co.uk or sign up FREE at www.facebook.com and get involved!

# Colostomy Reversal

Perhaps you are trying to decide whether to have a reversal. Stomas are formed for a variety of reasons. Different people will have had different types of operations - how much and which part of the bowel has been removed will vary, some people may have a loop stoma, others an end stoma.

More than 60% of colostomies are permanent and cannot be reversed. For those that can be reversed the outcome will vary depending on the reason the stoma was formed and how much, and which part, of the bowel has been removed.

Tidings asked four people who have had a colostomy reversal how they felt before and after the operation, here are their experiences...

## Muriel Findlay

### Why did you have a colostomy?

It was bowel cancer. While I was waiting for an outpatient appointment I was admitted to hospital as an emergency with a perforated bowel. When I woke up in intensive care I had a colostomy.

### What was it like living with a stoma?

At first I was devastated. I knew what a colostomy was because I worked as an auxilliary nurse, but I never thought it would happen to me. The surgeon said it was permanent so I told myself, 'Well now you've got it, let's deal with it.'

And yes, I managed fine. Like everyone else there were problems initially: the stoma wasn't in an ideal position and I had a couple of leaks, but the stoma care nurse suggested a two piece bag with a convex flange and that sorted it out. A colostomy wasn't that bad; I accepted I would have it for the rest of my life.

### When were you told it was possible to have a reversal and how easy was it to decide whether or not to go ahead?

It was two and a half years later. When I went for my regular check-up my surgeon said he was leaving, and gave me the name of two other surgeons who were willing to take over my case. After various enquiries I chose one. When I went to see him he looked at my date of birth and said, 'Would you like an early birthday present? I'd like to try a reversal.' I was "over the moon". However, he warned me that when he operated he might find he couldn't do it, after all. I told myself if that happened I'd just carry on. I'd be disappointed but it wouldn't be the end of the world.

He told me to take my time and think about it, discuss it with the stoma care nurses, talk to other people. I couldn't find anyone who'd had the operation so I rang the C.A. and they put me in touch with two ex-colostomates. One told me about the problems she'd had after surgery, but neither of them regretted their decision to go ahead. I read a letter in Tidings from someone who had lots of problems following their reversal which frightened me a bit.

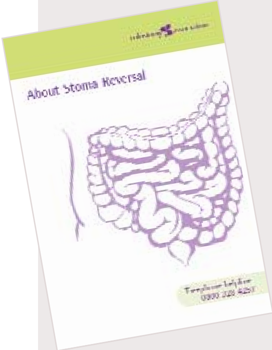
In the end I decided to go for it. After the op I would give it time. If I found I wasn't happy or couldn't cope, then I could always go back to having a colostomy.

**For more information...**about stoma reversal - register online at: **www.colostomyassociation.org.uk** then click on **Find Information** where you will find our leaflets.

Alternatively, **write to:**
Colostomy Association
2 London Court East Street
Reading RG1 4QL

or **email:**
cass@colostomyassociation.org.uk

or **telephone:**
0118 939 1537



to obtain your copy of our leaflet **"About Stoma Reversal"** which contains articles written by a surgeon and specialist nurses as well patient experiences.

## How long did you have to wait for your reversal operation?

I was lucky. In June 2005 I told the hospital of my decision and the operation was carried out on 25th July.

## Tell us about your operation and how you felt afterwards.

They went in through the same scar and rejoined my bowel. To allow the join to heal they formed a temporary ileostomy. I found this harder to cope with than a colostomy as I needed to empty the bag four or five times a day. When I went home I developed an infection and had to be readmitted to hospital for a week. This was when I began to wonder if I had done the right thing. However, with antibiotics it cleared up and I went home, then I came back for the ileostomy to be closed on 28th November.

Afterwards I felt a bit apprehensive because, after two and a half years with a stoma, I would be opening my bowels in the normal way. At first I was passing motions more frequently. I did have a couple of mishaps and persuaded the nurses to leave the commode beside my bed…just in case. However, once I got home and returned to my normal diet I found that my bowels behaved better than they had before I had my stoma: then I had alternating bouts of constipation and diarrhoea – now I went every day at the same time.

## How long is it since your colostomy was reversed and how do you feel now?

It is now almost four years. Occasionally, perhaps once a fortnight, I get a sudden urge to go, but I manage to cope with that. The rest of the time things are fine. So, yes, I'm sure I made the right decision. ■

**Derek Eastman**

Derek with his wife, Heather, on holiday in St Kitts

## Why did you have a colostomy?

It came completely unexpectedly. One Thursday in October 2008 I was struck with the most severe stomach pains and was admitted to hospital as an emergency. I was in hospital for two days before I was diagnosed with a perforated bowel. The surgery took place on Sunday night and on Monday morning, when I was aware of my surroundings, I realised I had a pouch fitted over a stoma.

## What was it like living with a stoma?

My mother had a stoma forty years ago and I was marginally aware from her experience of living with one. In my own case I was anxious about going too far from home or not being in easy reach of facilities for draining or changing the pouch. There was also the obvious anxiety of noisy wind in public places. Additionally I had concerns about running out of pouches etc. I was in hospital for four weeks and off work for four months which provided a good grounding in living with a stoma. My anxieties however quickly faded as my experience grew. It did not make any real difference to the way I lived my life. My wife and I had a week in Tenerife in June, our first holiday with my stoma, and everything worked out just fine.

## When were you told it was possible to have a reversal and how easy was it to decide whether or not to go ahead?

I was told following my surgery. In fact Heather was told before me, at one of her meetings with the consultant. We were told that it could not take place for at least six months after healing in order to prevent adhesions. I wanted it as soon as possible and initially the months could not pass fast enough. However, as I got used to living with the stoma I wondered whether a reversal would be the right way forward. It was not until I was in hospital waiting for the reversal surgery that I finally made up my mind - prior to that I was anxious that "something might go wrong".

## How long did you have to wait for your reversal operation?

Ten months. There was some initial delay as I had a further surgical procedure to remodel the stoma in January 2009. It had stenosed and retracted in the weeks following surgery. The consultant initially advised the reversal could not be before June 2009. I had my final consultation in July and the surgery went ahead in August 2009.

## Tell us about your operation and how you felt afterwards

The operation went extremely smoothly and I experienced no after effects other than some soreness. The consultant said that there had been no problem with the reversal. I awoke without a pouch, which felt good, but it felt a little strange the first time I went to the toilet. I was discharged after eight days and felt fine. In the following three months, however, the operation wound did get infected on three occasions and took some time to heal. I must admit to some anxiety that problems might have arisen with the "join" separating but it quickly passed.

## How long is it since your colostomy was reversed and how do you feel now?

Three months and I feel fine. Other than the scars it is almost as if I have never had a stoma. Everything works the way it should. I returned to work after three months and, other than still needing to be careful with lifting, life is fully back to normal. ■

# Lisa Tubbs

## Why did you have a colostomy?

I suffer from endometriosis. After a routine laparoscopy operation to laser off the adhesions, I developed complications. The doctors had pierced my bowel and a fistula formed. I had emergency surgery to form a temporary colostomy.

## What was it like living with a stoma?

Life with a stoma was very strange. It was always on my mind and I found it hard at times but overall very manageable. It was hard to come to terms with, especially as it had been as a result of an accident during the operation. As a twenty-six year old it wasn't something I was familiar with, or comfortable to discuss. I tried my best to always hide it and try to get on with life as I had before. I often felt nervous in case someone bumped into me and I worried about accidents.

## When were you told it was possible to have a reversal and how easy was it to decide whether or not to go ahead?

I found out I was having a colostomy the day before they operated, I also knew then it would only be temporary as it was to enable the fistula to heal itself rather than having a bowel resection. In all honesty for me there was no decision, I couldn't imagine my future with a stoma. That might have been different if I had suffered with bowel troubles prior to the stoma. I never saw it in any other way and knowing it wasn't permanent is what got me through the hard times. I was positive a reversal would work and I didn't worry about any potential problems.

## How long did you have to wait for your reversal operation?

When I had the stoma formed it was planned that it would be reversed about six months later.

## Tell us about your operation and how you felt afterwards

Combined with having a reversal I also had a bowel resection and part of my rectum removed. In comparison to previous operations I'd had, this was major surgery and not a straight forward reversal. The operation itself took about six hours and recovery was a lot longer and harder than it was after the stoma was formed.

With all my nervousness and upset about having a colostomy bag and the stigma and worries I built up in my head, I was surprised when I found it tougher to recover from the reversal. Because the reversal wasn't straight forward, I was in more discomfort and I was weaker than after the previous operations. The longer anaesthetic and the more invasive surgery really tired me out. For the first four weeks I was continually on the toilet having urgent, frequent and constant spasms with the need to pass stool. My brain was re-teaching the remaining bowel and rectum how to work and I had to work with it to try to learn when to ignore the incorrect signals. In the early days I was going to the toilet about fifteen times a day. Over the next three months this reduced down to about eight times a day, and then after about a year it has have evened out to about three times a day.

## How long is it since your colostomy was reversed and how do you feel now?

It's been three years this month and I feel great. I really feel back to normal and don't suffer any problems or pain. Going to the toilet several times a day is just normal to me now.

Having a stoma is very manageable, so when you first have a reversal you miss the ease of it. Once I felt better and the frequency calmed down there was no looking back and it was worth every bit of it. ■

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**Melanie Jayne Evans**

## Why did you have a colostomy?

I had an emergency operation as a result of a ruptured colon in March 2008. I was forty-two years old.

## What was it like living with a stoma?

I accepted my stoma immediately as it saved my life. I will admit I was in a state of shock –waking up in intensive care with this “alien” attached to my left side but after being given information about it by the stoma care nurses and surgeon I was fine.

## When were you told it was possible to have a reversal and how easy was it to decide whether or not to go ahead?

I was told immediately after my operation that my stoma was only temporary. The decision for me wasn't that difficult as I had come to the conclusion that I wasn't bothered either way - whether it could be reversed or not - as it didn't affect my lifestyle at all.

## How long did you have to wait for your reversal operation?

The reversal was carried out in April 2009, thirteen months after the original operation.

## Tell us about your operation and how you felt afterwards.

The operation was performed via keyhole (laparoscopic) surgery. My surgeon explained that this type of surgery is not always successful and can cause leakage, leading to another operation via open surgery. However, he also stated its advantages: a much quicker recovery and a shorter stay in hospital.

I went into hospital on April 19th and had the pre-op preparations - taking Picolax to empty the bowel - and the op was done on the 21st. It was a complete success. I was a bit nervous about “going” for the first time, but everything went well and I had no problems!

I felt much better after this op as it was done via keyhole. I was out of bed forty-eight hours later, with catheter and drips already out, and I was discharged on 29th April. My stoma nurse gave me contact numbers and she and her colleagues rang me at home to see how I was. They also said that I could pop into the stoma clinic if ever I had problems or concerns.

## How long is it since your colostomy was reversed and how do you feel now?

It has been seven months now since the reversal and I feel fantastic. It was successful and I have had no problems so far. ■

## If you have to decide whether or not to have a reversal:

Make sure you understand why your stoma was formed in the first place.

Ask your consultant or nurse specialist to provide you with detailed information regarding the proposed surgery and the realistic outcome you can expect in relation to hospital stay, length of recovery, and expected bowel function both in the short-term and long-term.

Consider what your quality of life is like with a stoma.

Consider what your quality of life would be like without a stoma, taking into account all the surgery and treatment you have had.

Speak to people who have undergone a similar procedure.

## Editors Comment

If you would like share your reversal experiences with the editor please e-mail:
editor@colostomyassociation.org.uk
or write to:
Colostomy Association
2 London Court East Street
Reading RG1 4QL
or email:
cass@colostomyassociation.org.uk
or telephone:
0118 939 1537

# Liking yourself

## written by Bob Buckley - CA volunteer

In a world where we are obsessed with image it is no wonder that self-esteem is often shattered especially when you find out you need an operation, which results in you having a stoma. Your most basic bodily function is taken away from you and you are left with a large scar, a stoma, and possibly side effects from other treatments, such as chemotherapy. Surgery is invasive and although it may be life saving it is also life changing and confidence can often take a knock. However, don't lose hope.

The first thing to do when you get out of hospital is to take stock. Your expectations may be high, but don't beat yourself up, take your time and follow medical advice. Initially being diagnosed with cancer occupied my thoughts. However, when I began to feel stronger and more like my old self all the doubts crept in. To me my stoma stood out like a sore thumb, I thought everyone would know I was wearing a pouch and would be able to smell it. One day my eldest son David said, "How many people with pouches have you ever noticed, Dad". I had to admit the answer was zero, to which he replied, "Why do you think people will notice you then?" This helped me get over one small hurdle, i.e. no one will notice your pouch unless you point it out. In fact in the days when I kept it secret even close friends didn't know, despite weekends away together, and were extremely surprised when I told them. To be honest most people are more concerned with their own appearance, not yours.

Another issue I was slightly paranoid about was if I disappeared to the loo to change my pouch, e.g. during a night out or at a dinner party I thought everyone would notice I was missing and comment. This never happened, have you ever timed anyone when they went to the loo? Of course not, you have better things to do.

Some ostomates worry about smells, this is natural but in today's stoma care product arena, we have variety and choice! There are a many different pouches available including flushable ones and accessories such as odour neutralising drops and sprays etc. Stoma care products such as the ones previously mentioned mean that smells are less of an issue now than they used to be. If you are a new ostomist and want help to find out what is available to you, ask your stoma care nurse. She will be able to advise you on what suits your particular needs. However, in Tidings as you will see there are various advertisements from stoma care product suppliers and if you ring them they are only too happy to send samples. You can also ring the Colostomy Association who will put you in touch with a volunteer who may also be able to help. Whatever you decide to do please don't suffer in silence.

Be upfront about your stoma, don't apologise for having one, you didn't choose it and it may have saved your life, having said that we are all different and most of us have suffered body image issues. I think it is important to value yourself; your stoma doesn't define you. What defines you are your life experiences, your interests, your friends and your family these things shape us and make us what we are. Think how your friends or family would describe you; try writing it down, most people would never see you differently because of your stoma, unless you encourage that situation.

We may feel we are no longer desirable to our partners, however we should not assume our partners feel the same and my advice is talk about it, if you love each other it will not get in the way and a loving relationship is very important on the road to recovery. For ostomates who are on their own talk to friends, family, fellow ostomates or join the Colostomy Association - it's good to talk! Talking is something you probably don't want to do at first but in my humble opinion it is fundamentally important in coming to terms with having a stoma.

Sometimes having a role model may help. My hero is Dame Tanni Grey - Thompson, probably the most successful disabled athlete in UK history. She is an articulate and exceptionally motivational speaker, positive and inspiring and when I listen to her I often forget her disabilities. To me her sporting prowess and her infectious personality define her. Being disabled has not stopped her doing most things, including becoming a mum. Dame Tanni is an example to us all and one we can learn from. Staying positive is not easy, if you are feeling uncomfortable in yourself making a change no matter how insignificant may help. It could lead the way to a happier you. No one is going to achieve that for us only we can only do that for ourselves.

Try to compliment yourself during your recovery and afterwards. You may have made your first trip out to the shop or had your first weekend away, say to yourself, well done! I'm making great progress, and of course you are! Try to stop yourself when negative thoughts come into your head - instead try to put something positive in their place and concentrate on the progress you have made.

When I had my surgery I told my colorectal nurse that a stoma wasn't going to get in the way of doing the things I love, it hasn't, but it was a much more challenging journey than I anticipated, so its not easy but don't give up!

You're not unique having a stoma, there are about 100 000 of us in the UK, but you are a unique and a wonderful human being so keep smiling, none of us would choose to have a stoma but don't let your stoma dictate your life. Your friends and family still love you so start liking yourself! ■

# Readers' writes

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

## Dear Tidings

Many thanks for sending me your very interesting information for a few years now. I have passed on the magazines to quite a few people I have met who have been through, or are going through, similar problems.

I had colorectal cancer in 1993 when I was thirty-nine. Fortunately it was diagnosed early. The tumour was removed, followed by chemotherapy and radiotherapy and a temporary stoma. This temporary ileostomy was reversed after three and a half years, because I asked for it to be. It was an unwise move because if there is no rectum left it leaves a happy person very unhappy with total incontinence. For years now my only solution is to have a permanent colostomy. Please let your readers know that with no rectum incontinence is a certainty they will have to deal with.

With many thanks,
**J.D. (Mrs)**

**Editor's Reply**
For other people's experience of stoma reversal see our special four page feature on pages 27 to 30.

## To: editor@colostomyassociation.org.uk

I would like to urge everyone, especially those with a recently acquired stoma, to ask someone in their support team if they have a problem. Do not, like me, assume that there is no answer – there usually is.
I had my colostomy operation a little over a year ago. Ever since then I have avoided visiting relatives and friends because of my perceived problem with the disposal of waste in someone else's home. I was fine in hotels with their level of relative anonymity. My recent attendance at a memorial concert for my cousin required an overnight stay and I worried myself into a high old state beforehand. Eventually I rang my stoma nurse hoping she would be able to say something to help me get things into perspective. Instead she said, 'Well you could try flushable pouches. They would probably solve your worries.'

Flushable pouches! I had no idea there were such things!

She arranged for me to have samples of two styles to try. I settled for the one-piece pouch, and a box was ordered. They worked beautifully. I do prefer my usual pouches for general wear, but the flushable ones are wonderful to use when I go visiting. My life can now get back to normal, and I can stop making excuses when my friends and relatives invite me to stay with them.

**J.D.W.**

## Dear Editor

When I moved to Kent eighteen months ago I enquired at the local council about the collection of clinical waste in my area. I was told that this was no problem and someone from the council called the following day with two rolls of yellow clinical waste disposal bags as used in hospitals. I put my used colostomy bags inside and every Wednesday morning these bags are collected from outside my front door. This arrangement works perfectly well for me and I wondered whether other colostomates would like to contact their council about this service.

Last, but not least, thank you for producing Tidings. It has helped me in many ways with information about the problems I have had. The latest one was about foods that may help to thicken the output. Eating cooked apples, pro-biotic yoghurt and ripe bananas, which I mix with honey, has made a big difference.

**Kind regards**
**M.D. (Mrs)**

## Dear Editor

### Perineal hernia

Having had a low anterior resection, plus radiotherapy, for a recurrent rectal polyp which turned out to be malignant, I was experiencing worsening continence problems. Eventually, in 2001, I had an A.P. resection with colostomy. The surgery included removal of my rectum, leaving a slight protrusion where my anus had been.
Recently I became aware of a

# **Readers’** writes

persistent dull ache, as though I had been sitting on a hard seat for too long, and that the slight protrusion had developed into a rubbery feeling bulge. Advice from a consultant surgeon is that I have a perineal hernia, which would require further major surgery to repair.

I understand that this is a relatively uncommon phenomenon, and would be interested to learn of the experiences of any others who might have developed this kind of hernia post operatively.

**M.A. (Ms)**

## Dear Colostomy Association

### Pouch changing with adhesive remover

Being fairly new to a colostomy I hardly think of myself as an expert, but a while ago a visiting nurse gave me a little aerosol of a medical adhesive remover, and I want to sing its praises. What a fantastic difference it makes to the pouch removal process.

For anyone who dreads the normal peeling off process or suffers from irritated skin associated with peeling off, I thoroughly recommend a little squirt of an adhesive remover. I had become used to a circle of somewhat pink skin after traditional pouch removal, but not any more. It is also very effective, and especially welcome, on adhesive that has become stronger due to perspiration or showering/bathing.

I believe that such products are available to ostomates on prescription in the UK or at a modest cost where this is not possible. So my advice is to get some medical adhesive remover and make peeling off a 'pleasure'.

I do not have any financial interest in these products, but I think they are fantastic.

**Thanks and regards**
**Adrian**

## Dear Editor

May I pass on a couple of tips that could be of use?

If when removing a bag I unfortunately pull a small piece of skin away, if it is near the edge of the flange then I cut a small amount of the flange away so the sore skin is not covered by the flange. It will then take a few days for the wound to heal.

If the sore area would be completely covered by the flange then I cut a small, maybe up to a half-inch square of dry wipe or lint and place this over the sore area to protect the wound. Thus when I remove the next bag the flange will not be in contact with the sore area of skin. It may take a few days of this protection to heal.

I use a one piece bag and occasionally the output fills the bag making it a little tricky to remove. I have found it is a good idea to slide an empty plastic disposable bag between my skin and the bag so the full colostomy bag is in the disposable bag. Then I carefully peel off the colostomy bag from the tip of the flange.

**Yours truly,**
**D.P.N. (Mr)**

## Dear Editor

I wonder if any other readers with a colostomy are registered partly sighted. I have to use a clear pouch and stand in front of a mirror to put it on. The shiny surface of the pouch reflects in the mirror making it hard to see whether I have placed the stoma pouch correctly. If the clear pouch had a dull surface I think it would make things a lot easier for people, like myself, who have poor vision. I would be pleased if someone has any ideas to overcome this problem.

**Yours truly,**
**W.T.**

## Hi

I am a member of the Colostomy Association and just wondered if you might be able to put me in touch with any other blind or visually impaired people? I would just like to know if they are able to cope independently with their stoma, if so maybe they can offer some tips. At present I have to rely on others to do this task for me, so having independence would be great.

**Best wishes**
**D.F. (Ms)**

**Editor’s Reply**
We would very much like to hear from any readers who have a stoma and a visual impairment. An article or a collection of letters on this issue could then be included in a future issue of Tidings.

**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**

Reader
PANEL
contributor

**Look out for our Reader Button to see where readers have contributed to Tidings**

**Yours**
**Rosemary Brierley**
**Associate Editor**

# **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 16....**
Thank you!

## Donations - In memory

| | |
|---|---|
| Eddie Rouse | £1580.00 |
| R M Reid | £ 100.00 |
| Mr G W Clinton | £ 145.00 |
| Mrs Kathleen Olwen Boyen | £ 219.10 |
| Mrs B Newbold | £ 228.00 |
| Mrs B Wooley | £ 100.00 |

## Lucky winners 500 Club

| | |
|---|---|
| Anonymous | £424.00 |
| Mr C Stanley | £212.00 |
| Mrs K Howe | £84.80 |
| Mr & Mrs I McLuckie | £84.80 |
| Anonymous | £84.80 |
| Mr L H Griffiths | £42.40 |
| Anonymous | £42.40 |
| Mr A J Reeve | £42.40 |
| Master E Taylor | £21.20 |
| Mrs S McGuigan | £21.20 |
| Mrs C Hulme | £21.20 |

There are still a few more place left in the **500 Club** - why not join in you could be on list next time!

### Thank you for YOUR donations...

- Mrs W. Benwell £60 in lieu of 90th birthday presents.
- S.Ahmed £100 to celebrate a successful reversal.
- S.Webber £50 gift from the Waldrons Chapel Christian Fellowship.
- Mr & Mrs Ward £80 received on occasion of diamond wedding.
- Truckle Cheese Co.£20, as a thank you for Monty Taylor selling cheese on their behalf at a local fayre.
- Throckley Drama Group - £200.
- Mrs M. E. Evans - £50 instead of sending Christmas Cards.
- £50 from residents of Hanover, Bradford.
- £26 from MJ Beynon, saving small change.
- £450 from North Tees Bowel Cancer support group, closed due to lack of new members.

## Fundraisers...

**Thank you** everyone for your kind donations

**Dear Sirs**
In June 2008 I had a colostomy after an emergency operation for diverticulitis abscess and perforated bowel. As secretary of the Castle Bromwich Wine Circle, we decided to hold a charity dance last July. I nominated the Colostomy Association to be the recipient
we raised £125. I find your magazine 'Tidings' to be very informative and reassuring to know that there are other people out there with similar problems.

**Yours faithfully,**
**Jackie Evans (Mrs)**

### World Ostomy Day Fashion show at High Wycombe organised by CliniMed/SecuriCare...

The CA was presented with a cheque for £375 from Maureen Kelly-Smith on behalf of CliniMed/SecuriCare. The fashion show held at High Wycombe to celebrate World Ostomy Day raised £368. Securicare/CliniMed increased this amount to £1500 which was split between ourselves, IA, UA and Beating Bowel Cancer. Our heartfelt thanks go once again to these wonderful companies.

### Terry Skydives for the CA...

Terry Dancy retired from her work as a Physiotherapist at Swanage Hospital due to a routine operation that developed complications. Terry divides her time between Dorset and the Costa Brava, where her next door neighbour just happens to be a skydiving instructor! So naturally the idea of doing a skydive for charity presented itself. The event was a really big deal for this 62 year old grandmother! The skydive took place in September 2009 and the money raised was divided between the CA and Swanage Hospital. Thanks Terry's fantastic (and very brave) effort we received a cheque for £610.

For pictures of the event visit:
www.terry-and.me.uk/skydive-pics.html

### Beth's Art exhibition...

Beth Miller who is 75 (pictured right with Janice xxxx) held an Art Exhibition in Tiverton last September. The preview evening raised £32.20 and the exhibition went on to raise a further £150 towards the £10,000 CA Appeal making a grand total of £182.20 for the appeal. The money raised was from donations, sale of cards and 10% from the sale of pictures.

The **Colostomy Association** would like to take this opportunity to say a **BIG THANK YOU** to **everyone who fundraised on our behalf during 2009.** We would not be here without you **- so PLEASE keep up the GOOD WORK!**

**Don't forget...the recycling appeal!** We need your old or unwanted mobile phones...telephone: 0118 939 1537 or email: cass@colostomyassociation.org.uk and we will send you a FREEPOST envelope. Simply place your phones in the envelope and return it to the recycling appeal. We will receive money for every phone sent on our behalf!

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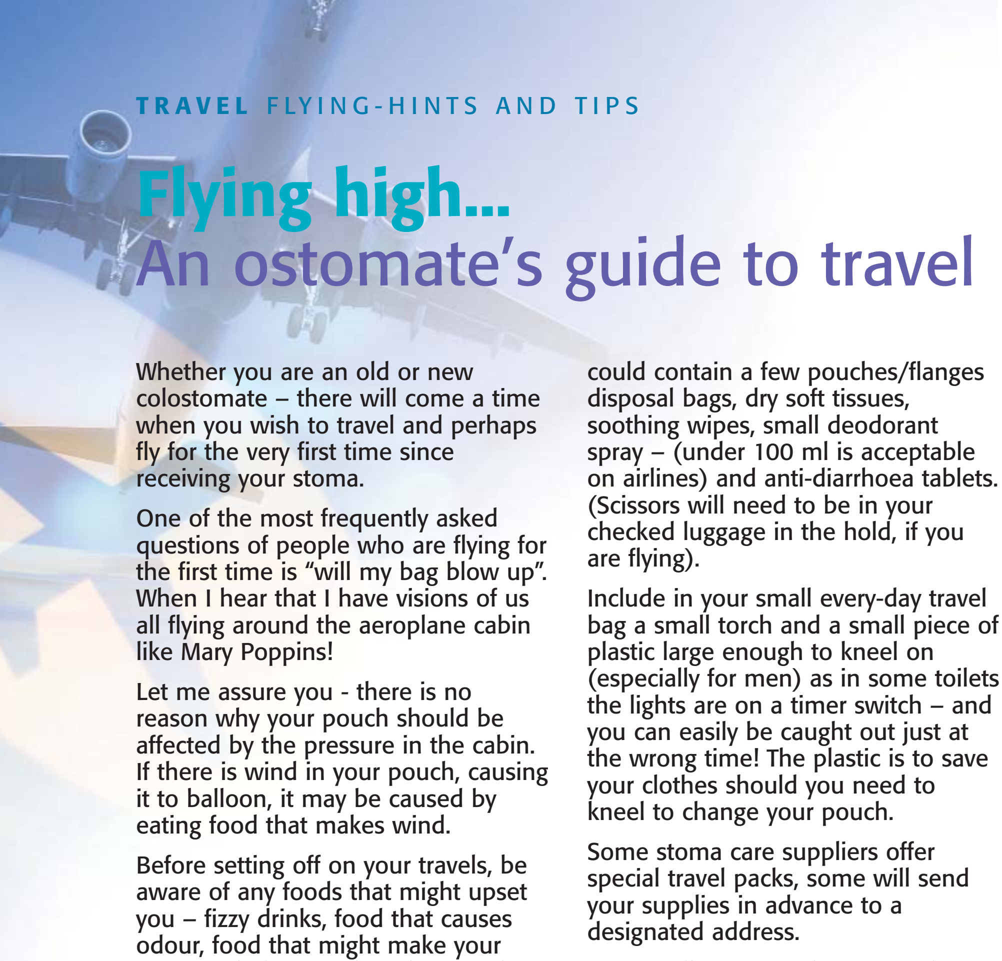

# Flying high...
# An ostomate's guide to travel

Whether you are an old or new colostomate – there will come a time when you wish to travel and perhaps fly for the very first time since receiving your stoma.

One of the most frequently asked questions of people who are flying for the first time is "will my bag blow up". When I hear that I have visions of us all flying around the aeroplane cabin like Mary Poppins!

Let me assure you - there is no reason why your pouch should be affected by the pressure in the cabin. If there is wind in your pouch, causing it to balloon, it may be caused by eating food that makes wind.

Before setting off on your travels, be aware of any foods that might upset you – fizzy drinks, food that causes odour, food that might make your output a little more liquid. Do make sure that the filter of your pouch is not covered, so ensuring that any wind can escape. If the pouch does fill with wind and the filter does not allow it to escape….a small pin prick in the filter should allow the wind to escape without causing any of the contents to leak out.

I am sure that you have given a great deal of thought to what supplies you will need on your holiday? It is always good to take at least twice the amount of pouches/flanges you need with you. A change of water, diet and even the heat can cause us to use more pouches than normal. It's better to bring some home rather than run out while you are away!

A good idea is to ask your stoma care nurse, to recommend a drainable pouch, (if you do not already use one). This will enable you to empty the pouch when you wish, rather than having to replace it. A drainable pouch is also useful when you are travelling and may not have access to disposal bins.

Taking your pouches and accessories with you in your hand luggage will mean that you keep them close at all times. To save space unpack your pouches/flanges from their original packaging and repack in clear-see through bags – (freezer bags or sandwich bags are ideal) place a prescription on top to show they are medical supplies. If you do not have a prescription a delivery note from your company will suffice. This is to stop anyone fingering the products to find out what they are. Your smaller bag could contain a few pouches/flanges disposal bags, dry soft tissues, soothing wipes, small deodorant spray – (under 100 ml is acceptable on airlines) and anti-diarrhoea tablets. (Scissors will need to be in your checked luggage in the hold, if you are flying).

Include in your small every-day travel bag a small torch and a small piece of plastic large enough to kneel on (especially for men) as in some toilets the lights are on a timer switch – and you can easily be caught out just at the wrong time! The plastic is to save your clothes should you need to kneel to change your pouch.

Some stoma care suppliers offer special travel packs, some will send your supplies in advance to a designated address.

We are all aware of the size of the toilets on board aeroplanes. Should you need to change your pouch make sure it is well wrapped up and placed in the bin. Using public toilets can cause the ostomate concern a good squirt of deodorant spray or perfume spray will ensure that you leave the toilet smelling sweetly. Another frequently asked question is about disposal of our pouches. Whether we are in the UK or abroad some of us get a little embarrassed to leave our used pouches in the open bins of a hotel bathroom. This is quite simply solved by wrapping them up well and placing them in a plastic carrier bag and on leaving the hotel disposing of them in the nearest rubbish bin or public toilet bin.

The Colostomy Association publishes an excellent Travel Guide and two types of Travel Certificates. These explain to the local immigration official that you have a stoma and if there is a need to examine you, a Doctor should be present. Keep it with you at all times.

A little thought before you depart on your travels will ensure that you will have confidence in your ability to cope while you are away from home. Sometimes it is hard to make and take that first step but with a little help and advice from the Colostomy Association, I just know that you are going to have a wonderful time. Don't forget to send us a postcard!

## Travel Insurance Update

**The following insurance companies specialise in providing cover for ostomates.**

**CATIP (CA travel insurance policy)**
A policy designed for ostomates by an ostomate. Contact preferred online any queries please call and ask for John Elias
Contact: 02920 668686

**Leisure & Lifestyle Insurance**
Specialist insurance for people who have a stoma, No age limit for single trips 75 for annual and then assessed
Contact: 08445 763029
www.leisureandlifestyleinsurance.co.uk

The following **insurance companies specialise** in **providing cover for cancer patients:-**

**Insure Cancer Medi Travel Cover Ltd**
Provides cover only for cancer related conditions, Please call for quote as each case is individually assessed.
Contact: 01252 780190
www.insurecancer.com

The **insurance companies** listed below **will cover ostomates.** We recommend that you contact at least four companies as quotes can vary.

**Age Concern**
Will insure pre-existing medical conditions and cancer with medical screening, No age limit.
Contact: 0845 6012234
www.ageconcern.org.uk

**All Clear Travel Insurance**
Will insure pre-existing medical conditions with screening. Annual policy age limit 70years.
Single policy no age limit.
Contact: 0845 2505250
www.allcleartravel.co.uk

**Chartwell Insurance**
Will insure pre-existing medical conditions with screening. Annual policy age limit 64. Single trip 79.
Contact: 0800 6524652
www.chartwellinsurance.co.uk

**Columbus Direct**
Please ring for medical condition/s cover, various offers can be up to 99.
Contact: 0800 0680060
www.columbusdirect.com

**Free Spirit**
Will insure terminal conditions. Phone for quote. No age limit.
Contact: 0845 2305000
www.free-spirit.com

**Go Travel**
They don't but can refer to others. 65 annual 99 single.
Contact: 0870 4211521
www.gotravelinsurance.co.uk

**JD Consultants**
Will insure pre-existing conditions with screening. No age limit.
Contact: 01689 859102
www.jdtravelinsurance.co.uk

**Leisurecare**
Covers cancer related conditions. Phone for personal service during office hours.
Contact: 01793 750150
www.leisurecare.co.uk

**Marks and Spencers Ltd**
20%cheaper if booked online. No age limit outside US - single trip to US 80, annual to US 75.
Contact: 0800 731 2424,
www.marks&spencer.com

**Travelbility**
Travel insurance company especially created for people who are disabled and those with pre-existing medical conditions. Subject to screening Annual 69 Single trip 79.
Contact: 0845 3381638
www.travelbility.co.uk

**Worldwide Travel**
Age 74 for annual and single trips.
Contact: 01892 833338
www.worldwideinsure.com

**Please note:**
**It is crucial to let your insurance company know of any pre-existing medical conditions. If not, the claim will be deemed invalid and rejected on the grounds of non-disclosure.**

**Planning a trip or holiday this year?**

The Colostomy Association has a Travel Advice leaflet that could really help you plan your journey. There are also two types of Travel Certificates available in European languages and Arabic, Hindi, Mandarin, Thai and Vietnamese.

**Contact: 0118 939 1537 and get your FREE copies today...**

# A partners perspective

# Living with an Ostomate

Janet Bray pictured with her husband and soulmate Richard Bray

Richard pictured left in the pits at Le Mans

My name is Janet Bray and I am the wife of Richard, who is the General Manager of the Colostomy Association based in Reading. I am 60 years old and work full-time in a small family owned hardware shop in Goring-on-Thames. I met Richard in Malta in 1969 and after a whirl-wind holiday romance, we married, we have been together now for thirty-eight years.

Richard who was born in South Africa, worked as a motor racing engineer for some of the biggest names in the business, Paul Hawkins, Ford AVA, Gulf Porsche, McLarens, Jody Scheckter, Tim Schenken, Chris Amon and Brian Redman to name just a few. Our courtship and first five years of marriage was a daze, we spent time in Capetown, Mozambique, Bulawayo, Le Chartre (24 hour Le Mans), Sicily and Monaco and rubbed shoulders with the great and the good, Princess Grace of Monaco, Elizabeth Taylor and Richard Burton and even spent a memorable evening with James Hunt at Rosie's Bar.

At this stage in our lives there was little to prepare us for the future, other than the fact that Richard had been very ill early on in his life, losing 3 stone in weight at the tender age of 16. At that time he had his appendix removed and was prescribed prednisolone for a time; Crohn's Disease was never mentioned or diagnosed.

During 1974/5 Richard's career path took a new direction. My Dad was Managing Director of the Grundon Group of Companies, specialising in waste disposal, aggregate sales and lorry/plant hire and, recognising Richard's hard-working, ambitious outlook, he employed him as temporary manager of their Reading depot. This was the beginning of a successful 30-year career in waste disposal during which time we also shared a working relationship as for 20 years I was accounts/wages clerk and general secretary at Grundons' Head Office in Oxfordshire.

1976 would prove a memorable year for us – Richard suffered a compound fracture of the right leg whilst playing in a 'friendly' works soccer match. During the operation to repair the bone the doctors suspected that there were underlying health problems due to the condition of his bones. And in September I gave birth to our first child, a daughter, Charlotte Louise.

Richard found himself in hospital again in 1977 this time to have an abscess drained under general anaesthetic. It was during this stay in hospital that Crohn's Disease was diagnosed. Doctors confirmed that this would probably have been the cause of his earlier health problems as a boy in South Africa. Richard then spent the next four years on various diets and went in and out of the John Radcliffe Hospital in Oxford.

An early treatment for Crohn's involved connection to a saline drip and having large amounts of steroids fed through the drip; then, after a week, food would slowly be re-introduced. This treatment was followed by an operation to remove a large amount of ulcerated intestine; then another spell on a drip – this time cyclosporine was introduced, the anti-rejection drug pioneered by Christian Barnard.

During the early 1980s, Richard was given a temporary Ileostomy for a year, but after being re-connected for a short while the Crohn's returned with a vengeance. He spent the next few years following various drug regimes to maintain his health.

Throughout all this I believe Richard's inner strength and incredible will - power kept him going – apart from actual stays in hospital, he rarely took a day off work and, as soon as any anaesthetics had worn off and he was able to sit up in bed, he was on the telephone to his office, writing reports and generally carrying on with his job

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We have produced a Life Assist pack with useful hints and tips on a range of ostomy lifestyle issues.

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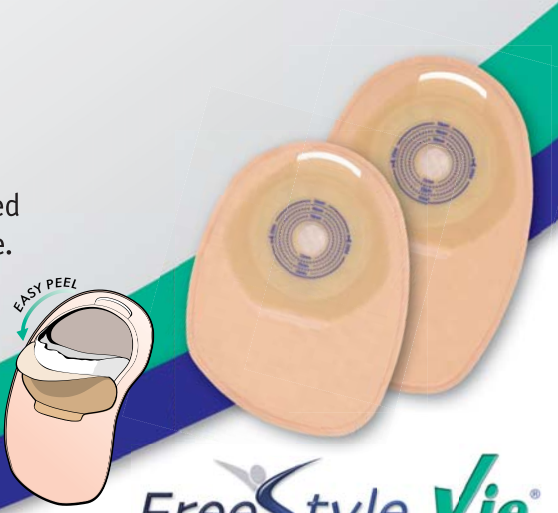

EASY PEEL

as much as possible, much to the chagrin of the surgeon and nursing staff!

Richard even ran the Reading half-marathon a week after leaving hospital one year, raising a large amount of money for the Crohn's in Childhood charity.

In 1987, after a great deal of soul searching and discussions, with my parents and sister (Mum had been a nurse and my sister Anne was a Ward Sister) Richard and I came to the conclusion that his quality of life would be greatly improved if he had a colostomy. Surgeons carried out the operation that year again at the John Radcliffe Hospital, Oxford.

Our youngest daughter, Georgie, born in 1985 has never known her Dad without his colostomy. As she was growing up, to explain the paraphernalia of an ostomate stored in the bathroom, we called him the 'mechanical man'! Yes, there can be difficult times, with 'accidents' when the bag bursts, or leaks, and there are shirts, pants, bed sheets to wash. Times like these can be very difficult for the ostomate. Richard is a very private person and meticulous about his appearance. Bag bursts and leaks can be very demoralising. When we are going through a difficult time I just remind Richard of how understanding he was when I wet the bed (when I was expecting one of the girls) and how we ended up laughing about it. Laughing in the face of adversity is generally what we do and thankfully we share the same robust some say quirky sense of humour!

During our relationship we have, as many people do, lived through a mixed bag of life's experiences - triumphs, tragedies, losses and gains. I consider myself very lucky to have had Richard's support throughout it all. Being an ostomate has not prevented him from raising a family, having a varied career, travelling the world or enjoying many sporting activities to a competitive standard. A particular passion of Richard's was water skiing, he was ranked in England as a veteran slalom champion in his 40s, he also enjoys clay pigeon shooting and golf.

For many years Richard trained the Woodland branch of the Pony Club Prince Phillip Cup mounted games team, of which both our daughters were members. Richard assisted at show jumping events, acting as groom/lorry driver/trainer in order to share our daughters' sporting passion (this was a man who had never been near a horse before our marriage!).

Earlier this year (2009) Richard discovered his 'perfect job', General Manager of the Colostomy Association, and is now enjoying being able to help others like him. He is living testimony that having a colostomy need not preclude a person from living a full and active life (and yes, that does include enjoying a normal sexual relationship – an extremely important part of our life together).

Richard's health problems continue as Crohn's disease together with large amounts of steroids over the years before his colostomy, have weakened his bones and surrounding tissue. But he just gets on with life and the challenges it brings. ■

# Adhesions and Blockages

## what are they...and how they may affect you

**Jeanette Berry CNS**
**Stoma Care**
Epsom General Hospital Surrey

What are adhesions? Abdominal adhesions are bands of tissue that form attachments between abdominal tissues and organs rather like an internal scar.

Normally internal tissues and organs have slippery surfaces, which allow them to shift easily as the body moves. Adhesions cause tissues and organs to stick together. This results in an abnormal bond between two parts of the body.

Adhesions may cause chronic abdominal pain and pelvic pain. They are also a major cause of intestinal obstruction (blockage) and female infertility.

### What causes abdominal adhesions?

Abdominal adhesions are most commonly caused after abdominal surgery by unavoidable handling of organs. It has been shown that adhesions that form after surgery are a result of the body's normal healing process and that they develop during the first three to five days. Almost everybody who undergoes abdominal surgery develops adhesions, however the risk is greater after lower abdominal and pelvic operations, including bowel and gynaecological surgery. They may become larger and tighter as time passes, causing problems years after surgery.

Adhesions that form after surgery are a result of the body's normal healing process. A less common cause is inflammation from sources not related to surgery i.e. abdominal, gynaecological infections and radiation treatment for cancer.
It is not unusual for several organs to be adhered to each other causing traction or pulling of nerves. Nerve endings may also become entrapped within a developing adhesion causing severe pain.

### How do they cause an obstruction?

Small bowel obstruction is a significant consequence of post surgical adhesions. The adhesions can kink, twist or pull the intestine out of place and prevent the flow of content through the digestive tract. A small bowel obstruction can occur 20 years or more after the initial surgery. A complete obstruction is life threatening and requires medical attention and often surgery.

### What are the signs and symptoms of abdominal adhesions?

Although most abdominal adhesions go unnoticed the most common symptom is chronic abdominal or pelvic pain. It may mimic other conditions such as diverticulitis and appendicitis.

Signs and symptoms may include:-

- Severe abdominal pain or cramping
- Abdominal distention
- Vomiting
- Loud bowel sounds
- Inability to pass flatus
- Constipation

A person with these symptoms should seek medical advice immediately.

### How are abdominal adhesion and obstruction diagnosed?

No tests are available to diagnose adhesions, and they cannot be seen through imaging techniques such as x-ray or an ultra sound scan. Most adhesions are found during exploratory surgery. An intestinal obstruction, however, can be seen through abdominal x-ray, barium and contrast studies and computerised tomography.

### How are they treated?

Treatment for abdominal adhesions is not usually necessary, as most do not cause problems. Surgery is currently the only way to break adhesions that cause pain, intestinal obstruction, or fertility problems. More surgery, however, carries the risk of additional adhesions and is avoided when possible. A complete intestinal obstruction usually requires immediate surgery. A partial obstruction can sometimes be relieved with a liquid or low residue diet. A low residue diet is high in dairy products, low in fibre and more easily broken down into smaller particles by the digestive system.

### Can abdominal adhesions be prevented?

Abdominal adhesions are difficult to prevent, however surgical techniques can minimise adhesions. Laparoscopic surgery avoids opening the abdominal wall with a long incision. Instead the abdomen is inflated with gas whilst special surgical instruments and a video camera are threaded through a few small abdominal incisions. Inflating the abdomen gives the surgeon room to operate. A film like material has been clinically trialed and has been shown to reduce adhesion formation when, if a large incision is required, it is inserted between organs or between organs and abdominal incisions. It looks similar to wax paper and is absorbed by the body in about a week. Other steps taken during surgery to reduce adhesions are using starch and latex free gloves, handling tissue and organs gently, shortening surgery time and not allowing tissues to dry out.

### How to avoid blockages

The output and consistency from your stoma may depend on the position of your stoma on your large bowel. After surgery good nutrition is necessary for healing as the body needs more calories and protein. You need to eat a variety of foods to ensure that you get the right balance. Initially some people experience excessive wind; this is normal and can take time to settle down. During this time certain foods should be introduced more gradually to your diet, as eating sensibly with a stoma is important to encourage regular bowel function. Remember eat in a relaxed atmosphere and at regular times. Don't eat and drink at the same time as this may cause wind. Enjoy small meals and eat little and often at regular times. Balance your diet and eat fruit and vegetables, avoiding only foods known to cause excessive unwanted reactions.

**Your stoma care nurse can give you the appropriate advice to meet your dietary needs. The Colostomy Association have a leaflet available entitled "Healthy Eating".**

To avoid blockages follow the guidance above. Eat regularly, have plenty of fruit and vegetables, take regular exercise and drink plenty of fluids especially in hot weather, approximately two and a half litres of water a day if you are able to. Avoid carbonated and caffeine based drinks. To lessen wind try fruit and peppermint tea, non-alcohol based drinks but if you had problems with wind before surgery this will not change after. However it is important to be aware that you can still become constipated or experience diarrhoea. It is important to remember that eating should be a pleasure!

**If you are concerned about blockages, diet or any of the issues mentioned in this article please discuss them with your stoma nurse.**

**References:**

The UK Adhesion Society
http:/www.adhesions.org.uk
National Institute of Diabetic and Digestive Diseases and Kidney Diseases
www.digestive.niddk.nih.gov

## Editors Comment

If you would like share your experiences with Jan contact the editor
e-mail:
editor@colostomyassociation.org.uk
or write to:
Colostomy Association
2 London Court East Street
Reading RG1 4QL
or email:
cass@colostomyassociation.org.uk
or telephone:
0118 939 1537

# Dear Nurse

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

**Q:** *I am due to have a reversal shortly. In July 2008 I had an emergency operation for inflammatory diverticulitis with abscess, perforated bowel and peritonitis. I was left with a 10 cm rectal stump and the surgeon said a reversal would be feasible but difficult. However, after a colonoscopy earlier this year, he put me on the waiting list for a reversal operation and I now have an appointment.*

*I have coped very well with my stoma, and have had no real problems at all, apart from a small parastomal hernia, which my stoma nurse said would go after the operation. I have read various things on the Internet about the variety of problems some people have with their stomas, and think I have been very lucky with mine.*

*I am getting increasingly nervous as the date for the operation draws nearer and I am uncertain as to whether I am doing the right thing. I have read some horrible things about bowel problems after the operation, it would appear multiple visits to the toilet every day are not uncommon, together with a lot of soreness. Does this get better with time, or is it always a problem?*

*I would love to hear from anyone who has had a reversal operation, were they pleased they went ahead, what is their life like now, do they miss their stoma, or do they regret going ahead, etc. Also, how does the second operation compare with the first?*

*I am dreading surgery again, as my original scar is quite large and goes right through my belly button.*

*I know every case is different, but I would be very pleased to hear of other people's experiences.*

**A:** You are correct to point out that everyone is an individual and that therefore there are many varying accounts of people's experience with regard to reversal of a stoma. The majority of patients recover very well post reversal and although initially they may find they have an erratic bowel, often needing to go to the toilet frequently in the early days, many people report this settles after a varying length of time. The majority of patients are happy with their toileting regime once things have settled, although there may be a few patients who feel it is a problem. If you have any doubts or concerns regarding your decision, I would suggest you speak to your stoma care nurse or your consultant, to ensure you are fully aware of the procedure and its potential consequences.

**Q:** *Could you please advise as to what I can do to aid evacuation of the anus, I've had a colostomy for nine years and this has been an ongoing problem, which I'm usually able to deal with, but in the past 24 hours, I have been very uncomfortable with great discomfort. I have tried suppositories and they have made little difference. I have started bleeding from trying to remove them and feel exhausted. What should I do next?*

**A:** If this is an ongoing problem for which you have used Glycerin suppositories with success in the past, it may be time to seek a review from your medical team who may be able to arrange for the stoma care nurse to give you a Microlax® or Arachus Oil enema to soften your output, or possibly even perform a rectal washout. It is possibly the impaction, which is causing the bleeding, but it may be worth discussing this with your medical team, as they may be able to offer a longer-term solution to this distressing problem.

**Q:** *I have a colostomy and get tired easily, I thought exercise might help but I don't know what would be suitable, can you advise me?*

**A:** You do not say how long ago your surgery was performed. This will impact on the type of exercise you are able to undertake. If surgery was very recent you will have to avoid strenuous exercise initially, gradually building up to more aggressive exercise as you feel able. If however the surgery was several months ago you can undertake different types of exercise, although if you have not exercised much recently you will still need to take things easy at the beginning and gradually build up. Gentle walking and swimming are a good starting point, gradually increase the amount you do and the frequency. If however you wish to join a gym/health club, I suggest you discuss your surgery with one of the fitness instructors so that they can ensure all the exercises offered are suitable. Hope this helps and enjoy.

**Q:** *I am 56 years old. Bowel cancer was diagnosed after a colonoscopy, just two weeks after seeing my G.P. for some quite obscure symptoms. I was, and still am, in complete shock.*

*I have recently had surgery, but unfortunately the surgery to connect the bowel after removing the affected length did not hold. I went back in to hospital two days after discharge and had a colostomy, which I am now struggling to come to terms with. I have found the whole episode very distressing.*

*Since the surgery, I have been trying to cope with a deeply inverted stoma, I have also been passing foul smelling mucus some times up to four times a day from my anus. Normally when I empty my bladder the mucus comes away at the same time. During the process my bowel feels like it's trying to push out my innards, I suffer with a lot of pain in my back passage and it hurts to sit down afterwards until the bowel relaxes. My bladder also feels like it's pushing out and I have pain on emptying it but not like cystitis. I am still taking painkillers every 4-5 hours. Are these normal symptoms after surgery? Please could you advise?*

**A:** As your surgery was very recent and you are struggling to cope and are having all these symptoms, I would suggest you speak to your stoma care nurse as soon as possible to organise a review from your surgical team. She may also suggest some practical solutions if you are having pouch related problems and some help psychologically as this is obviously a traumatic time for you. It is not unusual for people in your situation to react like this especially as you were not expecting a stoma, you may need more psychological support. The symptoms you describe are not uncommon, but yours seem to be particularly severe and I would therefore suggest a review.

**Q:** *My six-year-old daughter has a temporary stoma, which has prolapsed. We are going into hospital shortly to have this resolved. However one thing the hospital has not advised us about is how soon after the operation can my six year old resume her normal day-to-day activities. Her original colostomy prolapsed shortly after her operation even though she did not participate in any exercise for at least three weeks. Is it just down to bad luck? Her stoma is sited in her right upper quadrant because she may have a weakness in the usual place due to two previous hernias. Any advice that you could give post surgery would be gratefully received.*

**A:** You do not say exactly what treatment or how they are going to operate on your daughter during her next admission. If the surgery is performed laparascopically (keyhole) then the recovery is faster. However as she has had previous hernias it may be worth speaking to your stoma care nurse she suggest a referral to the physiotherapy department for some expert advice on exercise post-operatively to help her strengthen her abdominal muscles and hopefully prevent any further problems. The physiotherapists should be able to give advice regarding which exercises/activities are most beneficial and which should be avoided, especially during the early days of recovery.

**Q:** *I wonder if you can advise me please. I had a stoma done last year. Since then my problem is, I feel I want to open my bowel most of the time. I went into hospital to clean my bowel to no avail. I have asked for a proctectomy, which my surgeon is adverse to, as I have a super pubic catheter. I have had a scan to rule out my uterus putting pressure on my bowel. What do you suggest?*

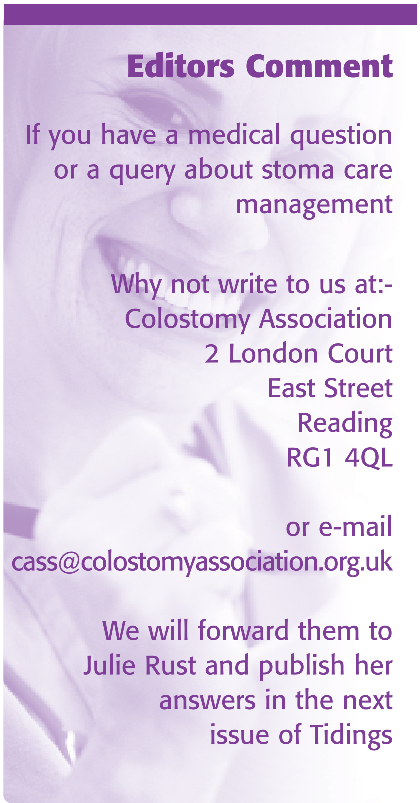
**A:** I'm afraid you seem to have covered most of the options already. I am presuming the feeling of needing to go to the toilet is from your rectum. I would usually suggest using Glycerin suppositories to help to control this feeling and to ensure the rectum is empty. This may need to be done on a regular basis and some patients learn to insert these themselves. Alternatively you may need to have the back passage washed out, which by the sounds of it you have already tried. It may, however, be something that you need to do regularly and I would suggest discussing it with your surgeon and stoma care nurse.

**Q:** *I am writing this to enquire as to whether you know of any belt type of appliance that I could use to hide the bulge of my prolapsed stoma.*

*I have had my colostomy for twenty-five years and have learnt to live a fairly normal life with it. Apart from the noises it makes and the odd leakage (due to scar tissue) all is as well as can be expected.*

*The more I think about the type of belt I need the more I realise it is purely for my own vanity but I feel it would make a big difference to my quality of life.*

**A:** There is a support belt available with a prolapse support section. It would be worth contacting your stoma care nurse for her to assess the suitability of this particular belt, she may be able to arrange a sample for you to try. The belt with the optional prolapse support is made by Nu-Hope Laboratories in California and is available through Penlan Medical over here. I hope this helps to improve your quality of life.



## Editors Comment

If you have a medical question or a query about stoma care management

Why not write to us at:-
Colostomy Association
2 London Court
East Street
Reading
RG1 4QL

or e-mail
cass@colostomyassociation.org.uk

We will forward them to Julie Rust and publish her answers in the next issue of Tidings

# Spare Ostomy Supplies...

## If you have any spare supplies and would like to help any of charities below please contact them direct.

The **Hospices of Hope** are a UK charity who work to improve the care of terminally ill children and adults in Romania and surrounding countries, established in 1992. They are currently appealing for stoma bags and related supplies for Hospices Angelus, their country partner hospice in Moldova based in the capital, Chisinau.

### "Developing hospice care in South-Eastern Europe"...

All items are very gratefully received - pouches and accessories, also lotions, powder and gels - provided the latter are unopened.

We suggest that donors remove all the box packaging (reducing the weight and cost of postage), place pouches, etc., in a carrier bag, and include the label from the original packaging so items can be easily identified on arrival. Please also put a slip of paper in the parcel with your name and address so that we can acknowledge your donation.

Ostomates in the third world have to re-use supplies as very few bags are issued to them post-operatively as the cost of new supplies is prohibitive.

When Dr. Beynon gives talks she takes an example of an ostomy pouch she has seen patients use. The fabric bag is like an ancient bicycle inner tube with multiple puncture repairs.

The supplies go to hospitals and clinics in Romania, Afghanistan, Ghana, at present. Doctors visit these areas and have contacts on the ground - we are quite sure that your donations go to where they are needed most.

### Please send your spare supplies to:

**Hospices of Hope**
28a High Street, Otford,
Kent, TN14 5PQ
Tel: 01959 525110
Email: office@hospicesofhope.co.uk
Web: www.hospicesofhope.co.uk
Other organisations that accept spare ostomy supplies follow:-

**Jacob's Well Appeal**
2 Ladygate,
Beverley,
E. Yorks.,
HU17 8BH
Charity No. 515235
Tel: 01482 881162

**SCAR (Stoma Care and Recovery)**
Maggie Little John
1B Redburn Gate
Kilwinning Road
Irvine KA12 8TH
Contact: 07817736147
Email: maggielittlejohn@aol.com

**Diversions** - is a support group in the north west, offering days out and support to families. Their next activity day is 20 March 2010.

**For more information:-**
Contact: Melissa: 07816 513 889
or Jen: 07954 179 415
or write to: Diversions Family Support Network c/o 44 Westbank Road, Lostock, Bolton BL6 4HE
or email: diversions@live.co.uk

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## How to contact the Colostomy Association

**By Post: 2 London Court**
**East Street Reading**
**Berkshire RG1 4QL**

**By Telephone:**
**General Enquiries: 0118 939 1537**
**Helpline: 0800 328 4257**

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

## Helpful Groups & Organisations

Other Ostomy Support Associations...

- 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
  Tel: 0845 6436858.
  e-mail info@gayostomates.org
  www.gayostomates.org

Support organisations for medical conditions...

- Macmillan Cancer Support
  Freephone:
  CancerLine: 0808 808 2020
  YouthLine: 0808 808 0800
  www.macmillan.org.uk
- Cancerbackup
  Freephone: 0808 800 1234
  www.cancerbackup.org.uk

Macmillan Cancer Support and Cancerbackup have merged all telephone numbers and websites remain the same at the present time.

- National Association for Colitis and Crohn's disease
  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

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# Marketplace

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

If you have anything to sell, an event to advertise or a message to communicate, you can place a small-ad for as little as £20. Please contact the Editor - details and information can be found on page 5. Advertisements received before 18 January 2010 will be considered for inclusion in the next issue of Tidings. So, why not get in touch and let Tidings promote your business or service.

## 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 and it can be a very sociable event.

### List of forthcoming Open Days:

Venue: The Hucclecote Centre,
Churchdown |Lane, Hugglecote, Glouc
Date: Sat 6th Feb 2010
Time: 10am - 2pm
SCD Gloucestershire Hospitals

Venue: The Guildhall,
Market Square, Salisbury
Date: Wed 17th March 2010
Time: 2pm - 5pm
Salisbury District Hospital

Venue: St Mary's Church Hall,
Church Lane, Bedford
Date: Saturday 27th March 2010
Time: 11am - 2pm
Bedford Hospital SCD

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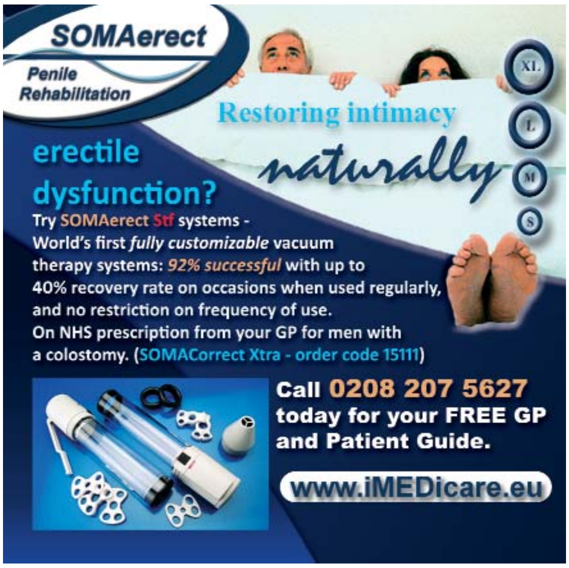

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**Telephone: 01205 723327 Linda Butler (a fellow Ostomate)**

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- The Sash belts are available on prescription and suitable for both male and female.
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- 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

## Security and Leakage Belt

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- 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.
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**Website:- www.sashstomabelts.com**

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:**

SASH Woodhouse Woodside Road Hockley Essex, SS5 4RU England
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# Support groups - make a difference

## by Jackie Dudley Trustee and organiser of West Berkshire Ostomy Club/Monday Pop In Group

Sometimes, when we first receive our stomas we feel as if we are the only one, so it is good to speak to others who are a little further 'down the road' and use their experiences to learn more about 'living with a stoma'.

No-one wants to be pushed into joining a support group or made to feel that they have to be part of one - however the benefits to ostomates who do attend are invaluable.

We recently received a wonderful e-mail from someone who was about to turn away from a support group meeting. The following excerpt from that e-mail shows how the group really made a difference to them…

*"It was at your meeting when my turning point came. When I peeped in the door that day and saw everyone I was going to turn around and leave because I knew I would have nothing in common with the group as they were all older than me. You spotted me and brought me into the room before I could run away. Every day I thank my lucky stars that you did.*

*I was so wrong - the common sense and practical tips I picked up that day have served me well. I sat with a gentleman who had been a pharmacist (like me) he advised me to buy a little torch on a headband as the lights in disabled toilets are on timers - how right he was! That torch has served me well over the last few months. I also chatted with a lovely man who had chosen to have a stoma as he had cancer; he wasn't a young man but bore things with such dignity and left me speechless. There I was 42 yrs of age, ready to give up and there he was, 91 (if memory serves me right) having survived (both physically and emotionally) not only the surgery but cancer treatment too. I didn't go through anything like that and yet here I was miserable and ready to give up. The two hours I spent with your support group changed my life".*

A support group as this excerpt shows, offers a safe and confidential haven where people can be themselves. Members can share personal stories, express emotions and be heard in an atmosphere of acceptance, understanding and encouragement.

If you have been thinking about starting a support group why not discuss the idea with your stoma care nurse. She may already run a support group and be able to pass on some valuable hints and tips to get you started.

### Starting a Support Group - here are a few Q&A's

**Q. How many people should I invite to attend my support group?**
**A:** The number will vary but start small to begin with.

**Q. How and where do I find a venue to hold my support group meeting?**
**A:** Investigate the possibility of a room at your local Hospital, Doctors' surgery or Community Centre they may offer one free of charge. Or contact your Borough Council or Voluntary Action Group and discuss your ideas with them. Then visit the venue to decide if it is convenient and welcoming and don't forget to ask if there are tea and coffee making facilities and ladies, gents and disabled toilets on the premises.

**Q. How often should I hold a support group meeting?**
**A:** This is really up to you as the organiser, why not discuss it at your first meeting and let your members guide you.

**Q. What should I call the new Support Group?**
**A:** A name is needed to publicise your group to new members and health professionals who will tell their contacts about you. Why not have a brainstorming session at your first meeting, it will be a good icebreaker and help everyone feel part of the new group.

**Q. Where should I advertise my support group meeting?**
**A:** Ask your stoma care nurse to advertise your group or place posters in your Doctors' surgery, local Community Centre, Library or District Council.

**Q. Who should I invite to my support group meeting?**
**A:** Your group could include colostomates, ileostomates and urostomates – and prospective members might like to bring family, carers and friends.

**Q. How can I ensure my support group meeting is a success?**
**A:** A successful group is based on enthusiasm and commitment., the goal being to achieve a happy and consistent support group.
A successful group respects and listens to what those around them are saying which ensures everyone can voice their opinions freely.

The **Colostomy Association** is happy to help with the promotion of your support group, they will help:-

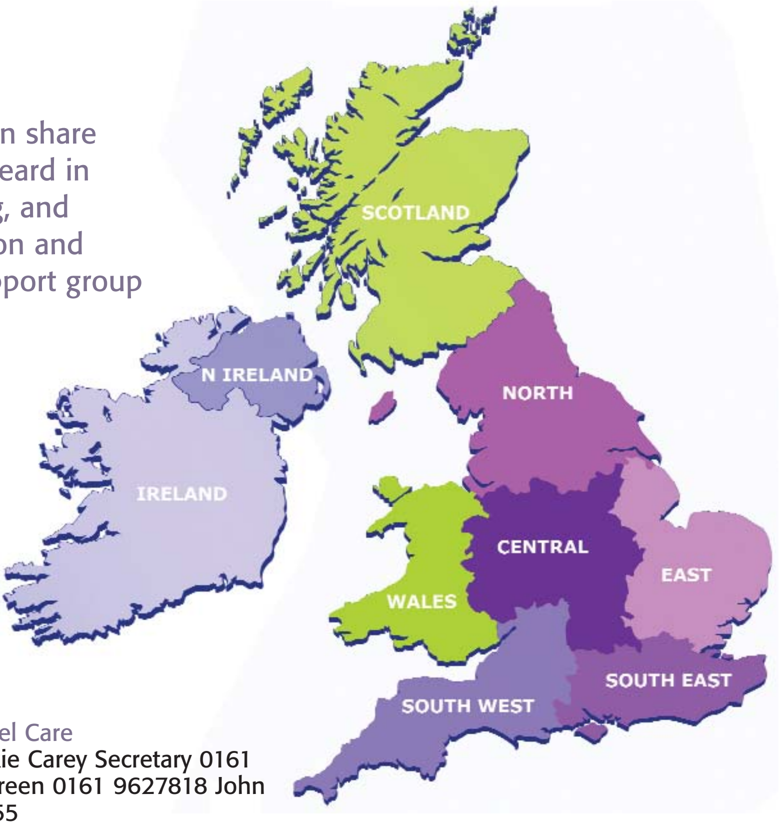
- design a flyer, which includes information about where and when your first meeting will take place plus they will help with advertising your event by sending your flyer to Colostomy Association members in your area.
- design a poster to publicise your first meeting.
- give advice on how to obtain funding for your group.
- provide contact details of stoma care companies who will be delighted to support your event by coming along to your meetings with products and samples.
- advise you on what leaflets are available and provide literature for you to display.

**Running a support group – large or small – is a worthwhile and satisfying venture. The difference you can make to others is enormous!**

## Editors Comment

If you would like to speak to
Jackie Dudley - Trustee
simply mention this in your
correspondence
contact the Colostomy Association
on 0118 939 1537
or email
cass@colostomyassociation.org.uk
for further information.

**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...

The following support groups have been revised thanks to your responses from the autumn edition of Tidings.

### Scotland

**Midlothian:**
GOSH
Contact: Alex Topping 01501 772154
Maggie's Edinburgh Timetable
Contact: 0131 5373131
**Glasgow:**
Fittleworth Support Group
Contact: Maureen (SCN) 0800 7837148
**Ayrshire:**
North Ayrshire Stoma Support
Contact: Jim 01292 220945
(S.C.A.R)
Contact: Maggie 0781 7736147 or John 01290 550551
**Fife:**
Fife Ostomy Support Group
Contact: Ishbel Barr 01592 772200

### England - North

**Cheshire:**
Stockport Support Group
Contact: Angela Simpson 0161 419 5059
Hand in Hand
Contact: Julie Davis Secretary
Cestrian Support Group
Contact: David Burgham 01244 310461
Warrington Ostomy Support Group
Contact: Jane Shaw 01925 662103
Countess of Chester Hospital
Contact: Julie Clements 01244 365490
Drop in Clinic
Contact: Angela Perks/Deborah Singleton 01625 661598
**Cleveland**
Oops Group
Contact: Julie Morrisroe SCN 01287284113
**County Durham:**
South West Durham Ostomy Group
Contact: Betty 01388-814535 Brian 01388 763684
**Derbyshire:**
Stockport Support Group
Contact: Angela Simpson 0161 419 5059
**Lancashire:**
Trafford Bowel Care
Contact: Jackie Carey Secretary 0161 7489659 Doreen 0161 9627818 John 0161 7484655
Oldham Stoma Support
Contact: June Wilde 0161 6787086
**Merseyside:**
Olivia Thomas Suite University Hospital
Contact: (Evening) Barbara Percy 0151 5292842
I.C.U.P.S
Contact: Carol Anderson 0151 3277589
Liverpool Support Group
Contact: Barbara Percy 0151 5292842 (Afternoon)
**Northumberland:**
Northumberland Cancer Support
Contact: Pat Fogg 0191 4102679
**Teeside:**
Bowel Cancer support (Semi Colon)
Contact: Mr G Dickson 01642 563747
**Tyneside:**
Gateshead Health NHS trust (Stoma drop in clinic)
Contact: 0191 4878989 ext 2221
Royal Victoria Infirmary Support Group
Contact: Gordon Weatherburn 0191 2341109
NHS Molineaux Centre
Contact: Lesley Brown 0191 2195656
**Yorkshire:**
Airedale Stoma Support
Contact: Jenny Shaw 01535 652516 or Sue Hall 01535 210483
Dewsbury & District Ostomy
Contact: Janet/Eileen 0844 8118110
Scarborough Stoma Support Group
Contact: Sister Jean Campbell 01723 342388
Rotherham Ostomates Caring Support
Contact: Karen Kilford 078880 575758
CROPS (Colo-rectal ostomy & internal pouch support)
Contact: Gloria 0114 2879503

**Isle of Man:**
Stoma Support Group
Contact: Carole 01624 650212
Optimistics
Contact: Stoma Nurse Lynne Webb SCN 01983 534009

### 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:**
North Notts Stoma Support Group (Sutton-in-Ashfield)
Contact: Tore and Nicky Norman 01773 715460 (Sutton-in-Ashfield)
Nottingham Colostomy, Ileostomy & Urostomy support group
Contact: Rosemary Brierley 0115 982 7868
Mansfield Stoma
Contact: Gerry Marshall 07794 159267
**Staffordshire:**
Outlook
Contact: Ernie Hulme 01782 324441 Joan 01782 710828
**West Midlands:**
Colostomy Group
Contact: Pat Keane 0121 4242730
Stoma Support Group
Contact: Anne Wilcox 01283 214389

## England - East

**Bedfordhire:**

Saturday Social Club
Contact: CA for details

**Essex:**

M.E.S.S (Mid Essex Stoma Support)
Contact: Clive Blanchard 01245 468750 Jeanette Johnson 01376 511862

North Essex Stoma Support
Contact: Mr W Hatch 01255 503688 Brian Waller Secretary 01206 540449

Redbridge Ostomists Club
Contact: Stoma Nurses: Chris/Lisa 0208 9708321

South Essex Young Ostomy Group
Contact: Paul Gray 01708 501268

Optimistic Ostomates
Contact: Janet 01702 385510 Angela 01702 385509

STEPS
Contact: TBA

**Hertfordshire:**

Colonise
Contact: CA for details

Stoma Fellowship
Contact: Karen/Mandy 01438 781133

**Lincolnshire:**

Friends Support Group
Contact: Betty 01205 724120/Sheila 01205 364493

Grantham Support Group
Bobbie/Amanda 01476 464822

**Norfolk:**

Stars
Contact: Anne Brown 01603 661751

Ostomy Frienship Support Group
Contact: Maureen Ford

**Suffolk:**

James Pagett Ostomy Support Group
Contact: Sandra Hutchings 01502 585955

East Suffolk Ostomy Group
Contact: Marion Fisher 01473 311204

West Suffolk Support group
Contact: CA for details

## England - South East

**Berkshire:**

West Berkshire Ostomy Club (WBOC) (Reading)
Contact: Jackie Dudley 01344 426652

Monday Pop In Group (Bracknell)
Contact: Jackie Dudley 01344 426652

**Hampshire:**

Southampton Support Group
Contact: Carol Summer 02380 446779

**Kent:**

Dover & District Stoma Support
Contact: Marie Culleton SCN 01227 769679

Ashford Stoma Support
Contact: Chairwoman - Ursula Naish 01233 640863

**London:**

Whipps Cross University Hospital
Contact: Christina 0208 5395522

Ealing Ostomy Support Group
Contact: CA for details

South Woodford Ostomy Support Group
Contact: CA for details

**Middlesex:**

Inside Out
Contact: Bob (chairman) 0208 4284242 Sarah Varma 020 82354110

Semi-Colon Club
Contact: 01895 179391

**Oxfordshire:**

Oxfordshire Ostomy Fellowship
Ernest Draper 01865 391257

**Surrey:**

Epsom and District Stoma Support
Contact: Jan/Sheena 01372 735232

**Sussex:**

Brighton & District Stoma care support (SAS)
Contact: Sylvia Bottomley 01273 554407

West Sussex Princess Royal Stoma Support
Contact: Tina Walker 01444 441881 ext 8313

The Ostomy Friends Group
Contact: Jane Quigley 01323 417400 Ext 4552

## England - South West

**Avon:**

Bristol Ostomy Self Support (BOSS)
Contact: Christina 0117 9558236 Joyce 0117 9075326 Rob 0117 9668021

**Cornwall:**

Optimists
Contact: Sue Hatton 01326 340058

**Devon:**

Devon IA
Contact: Margaret Bond 01392 447374

**Dorset:**

Cupid (Colostomy Urostomy pouch Ileostomy of Dorset)
Contact: CA for details

**Wiltshire:**

Wessex Stoma Support Group
Contact: Michael Slater 01722 741233

Swindon IA
www.swindon-ia.org.uk

## Wales

Blaenau Gwent Self Help
Contact: Marina Heal 01495 310686 (after 6pm)

Swansea Ostomy Self Help Group
Contact: Glynis Jenkins 01792 418245

Wrexham Ostomy Friendship Group
Contact: CA for details

## Northern Ireland

Daisy Hill Hospital Belfast
Contact: Bernie Trainor
028 3883500 Ext 2222

Mater Hospital Belfast
Contact: Karen Boyd
028 90741211 Ext 2329

Causeway Patient Support Group
Contact: Mary Kane 028 70346264

Southern Trust
Contact: May 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

RADAR
the disability network

NATIONAL KEY SCHEME

How to obtain a key to gain access to toilets for the disabled

Colostomates are entitled to a key which will open 7,000 locked toilets around the UK. Some local councils will provide this key free, or for a small charge.

Keys can be obtained from the Colostomy Association at cost of £3.50. Contact head office: 0800 328 4257 for an application form.

Keys can also be purchased for £3.50 from RADAR:
Tel: 020 7250 3222
www radar-shop.org.uk

RADAR also publish a guide which lists all the NKS toilets throughout the UK (cost £10.25).

## Editors Comment

Support groups are very often invaluable to those who are ‘Living with a Colostomy’. We support existing groups and help new support groups set up. If you know of a support group not mentioned in our listings please let us know.

Here’s how you can get in touch via e-mail:
editor@colostomy association.org.uk

or write to:
Colostomy Association 2 London Court East Street Reading RG1 4QL
or e-mail:
cass@colostomy association.org.uk

# Donation & Standing Order Form

## Thank you for your support

colostomy association

Please use this form to make either a **Single donation** or a **Regular donation** by **Banker's Standing Order.** 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 full name, address and postal code thank you

**My Details:**

Title: Name: Surname:

Address:

Postcode:

Telephone number: Email:

**1 Single donation:** (a donation of £12 or more covers production of four issues of Tidings per year)

☐ (Please tick.) **Yes** I would like to make **an single donation**

I would like to make a donation of £

I enclose a **cheque/postal order form** made **payable** to the **C.A. Ltd - Thank you!**

☐ Please tick here if you require a receipt acknowledging your kind donation

**2 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.)

☐ (Please tick.) Yes, I would like to make a **Monthly** donation of £
☐ (Please tick.) Yes, I would like to make a **Quarterly** donation of £
☐ (Please tick.) Yes, I would like to make a **Yearly** donation of £

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

To the Manager: (Bank or Building Society)

Bank Address: Postcode:

Name(s) of Account holder(s):

Account number: Sort code:

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

Account name: **C.A. Ltd** Account No: **88781909** 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:** / / 20

giftaid it

**Thanks to the gift aid scheme** - we can reclaim money on your donation from the government. **For every pound you give us, we can claim an extra 28p.** For example, a donation of **£15 becomes £19.23 with gift aid,** at no extra cost to you.

☐ I would like the tax to be reclaimed on any eligible donations that I have ever made or will make to the Colostomy Association until further notice. I confirm that I pay an amount of income tax and/or capital gains tax at least equal to the tax that the Colostomy Association reclaims on my donation in the appropriate year (currently 28p for every £1 donated).

**Signature:** **Date:** / / 20 **Thank you for your gift**

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

# 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!**

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

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

**The Association provides:**

- 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 themselves ostomates) these dedicated individuals bring a human touch.
- 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'.
- a voice for your opinions at on going 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

- **Single Donation**
  Single donation from individuals and fundraising events are always welcome and greatly appreciated. So please keep them coming, no matter how small. Just £12.00 (or more) ensures we are able to continue to produce four issues of Tidings per year.
- **Regular Donation**
  Regular donations can be made via standing order (see Donation Form) Regular donations help us to plan ahead and like all donations are vital to our survival.
- **Donate via Payroll Giving**
  Enables you to give direct to us straight from your gross salary (before tax is deducted), and to receive immediate tax relief of up to £4 for every £10 donated.
- **Legacies - 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 to help us to continue to offer support to all those with a colostomy.

**NEW...Donate online simply register at www.colostomyassociation.org.uk and click the donate button in the main horizontal menu and go to donate-online**

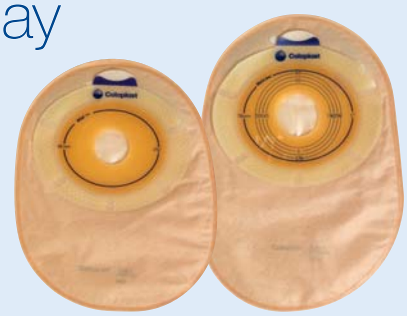
Together we can make **a difference** to the everyday lives of **fellow colostomates... by giving today** you ensure the Colostomy Association will be here **tomorrow!**

**Your donation** to the **Colostomy Association today...**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**

colostomy association

Office Address: 2 London Court, East Street, Reading RG1 4QL Tel: 0118 939 1537 Helpline: 0800 328 4257
E-mail: cass@colostomyassociation.org.uk Web: www.colostomyassociation.org.uk
Registered Office: 2 London Court, East Street, Reading RG1 4QL
Registered Charity No: 1113471

# Order your **FREE** ***SenSura*** Split Soft Cover samples today



☐ **Midi** ☐ **Maxi**

☐ I require Convexity: We advise you call us directly if you require a convex product, as we cannot supply these products without advice from your healthcare professionals: **0800 220 622.**

Please specify the size of your stoma: ☐

Do you have a template? ☐ Yes ☐ No

Does Coloplast have a copy of this template? ☐ Yes ☐ No

Please note, not all products are available in all sizes. If you select an option that is not available, we will send you the nearest option.

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Alternatively, visit **www.charterhealthcare.co.uk**
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☐ Please confirm, by ticking the box, that you would like Coloplast to keep you updated on new products and services, and that in order to do this you are happy for the Coloplast group to hold personal data about you in its database.

**Signature** ........................................................................ **Date** ......................

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For product enquiries and to order samples, please call our freephone number **0800 132 787.**

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Coloplast

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