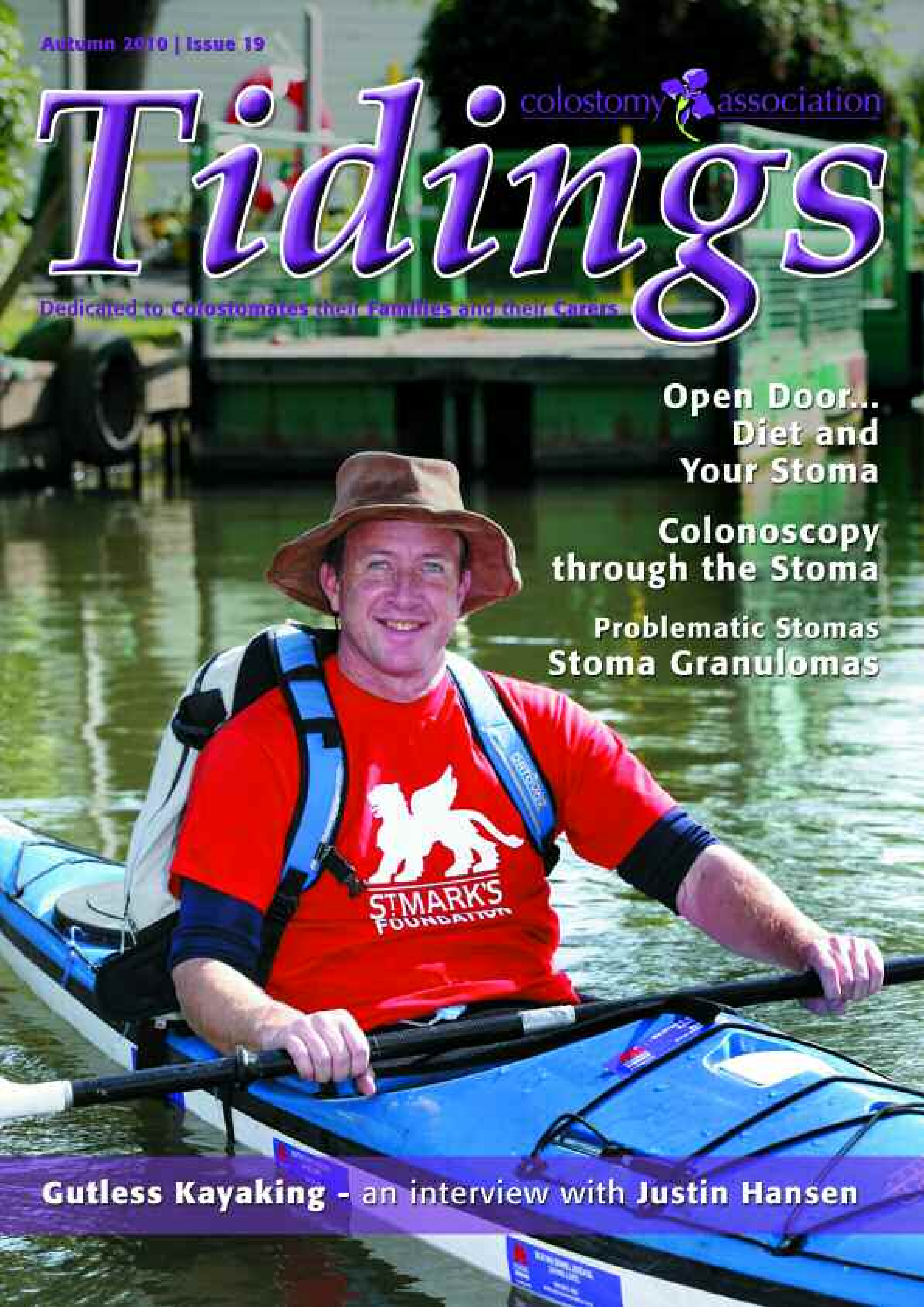
Autumn 2010 | Issue 19

colostomy association

Tidings

Dedicated to Colostomates their Families and their Carers



Open Door... Diet and Your Stoma

Colonoscopy through the Stoma

Problematic Stomas Stoma Granulomas

Gutless Kayaking - an interview with **Justin Hansen**

THE Natural CHOICE FOR A PERFECT FIT

NEW Natural fit

Excellent flexibility and adhesion, to fit closely to any body shape, ideal if you have a hernia

Flexifit® wafer on a hernia

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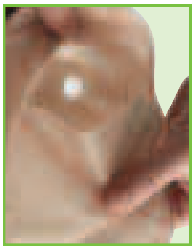
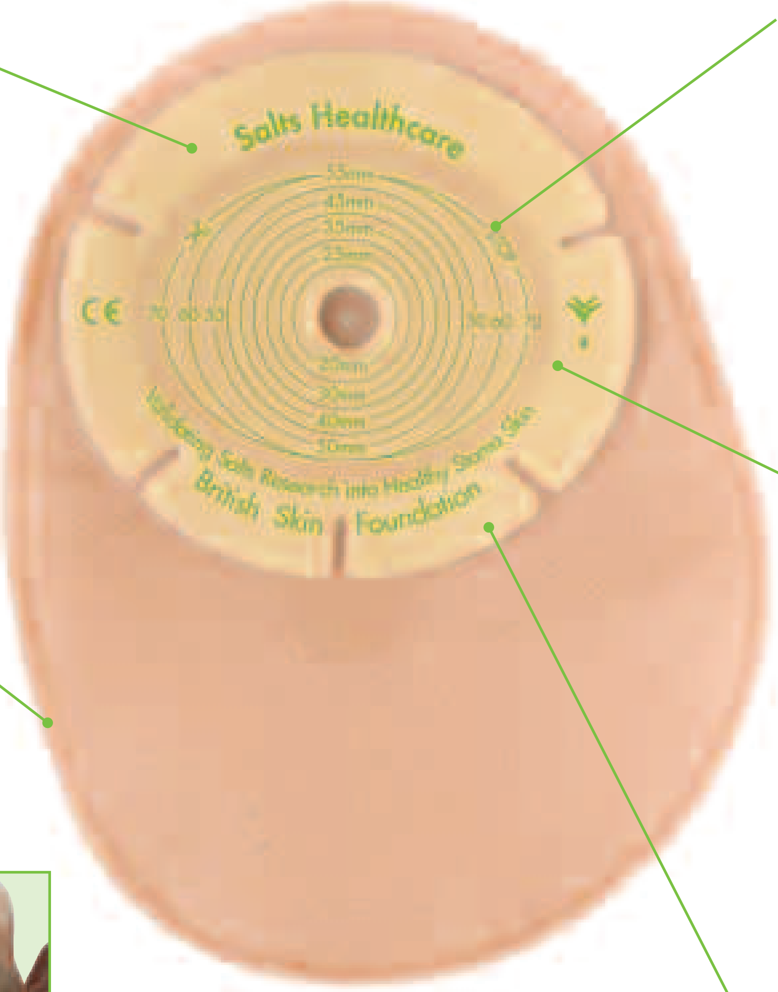
Soft edges for increased comfort





NEW Natural softness

Infused with Aloe extracts for softer skin

NEW Natural shape

Unique Flexifit® wafer bends and flexes with your body

BRITISH SKIN FOUNDATION

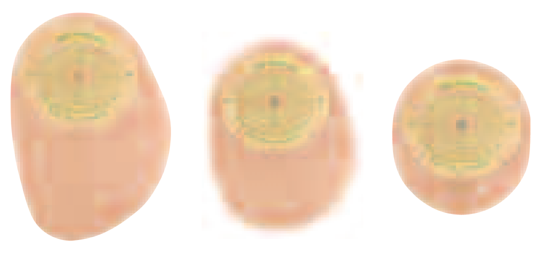
NEW Natural protection

Skin-friendly hydrocolloid, research into which is validated by The British Skin Foundation

As a colostomist, who has ever suffered from an ill-fitting pouch, leaks or sore skin, it's time you discovered NEW Confidence® Natural. Now, users can have all the comfort and convenience of a one-piece closed pouch with a range of natural benefits.

NEW Confidence® Natural features a unique, five-sided Flexifit® wafer, so it offers greater comfort, flexibility and fits more securely to the body's natural contours. It's even infused with extracts of Aloe Vera for smoother, softer skin.

AVAILABLE IN LARGE, STANDARD OR MINI



For free samples or further information, please call FREEPHONE 0800 626388 or visit www.saltsstomacare.co.uk

Confidence® Natural
WITH ALOE EXTRACTS

SALTS
HEALTHCARE

welcome to AUTUMN

Did you know...

CA has Two Travel Certificates...

available with information translated into different languages:

- French, German, Italian, Spanish, Portuguese, Greek, Turkish, Croatian, Polish & Russian.
- Thai, Vietnamese, Arabic, Hindi and Mandarin

Helpful information Guides...

Two excellent booklets are available from The Community Legal Service...

- Community Care - No.7
- Claiming Benefits - No.C10

Contact: 0845 345 4 345
or visit:
www.communitylegaladvice.org.uk

The response to the summer issue of Tidings was excellent and the Colostomy Association and Editorial Team would like to thank everyone who sent in donations, letters to Dear Nurse, ideas for new articles, requests for literature, emails and queries.

I am pleased to say, this is exactly what I and the Editorial Team had hoped for, however, it doesn't mean you can stop now! No! Towards the back of this issue of Tidings is a Feedback Questionnaire – from time to time we need to know that the content of the Magazine is fulfilling our readers interests. Some 19,500 Tidings are printed and the readership is widening. It includes colostomates, their partners, family members, carers, other ostomates, support groups, stoma care nurses, colorectal nurses, GP's and surgeons. So, please fill in the form, detach and return it to Head Office by 31st October, addressed to - Tidings Editor - many thanks! I expect an overwhelming response please don't let me down!

Our Open Day…is coming up fast and all are welcome; you will find more information on Page 13. It is on Saturday 16th October at the Heritage Motor Centre, Warwickshire and includes FREE entry to the centre until 5pm. Contact Richard Bray – General Manager for more details or ring Head Office on 0118 939 1537 to book your place!

I am delighted to welcome two new contributors to Tidings, Toni Johnson RN Dip NS, ENB 980, ENB 998 writing for Problematic Stomas about Stoma Granulomas and Sophie Medlin BSc RD who will write a series of articles entitled Diet and your Stoma, the first of which is our Open Door feature - questions and experiences relating to both series are most welcome. More work for you!

Recently, I have had time to reflect on this year's issues of Tidings Magazine. Turning the pages of each issue I find I am overwhelmed by the diverse and inspirational content. The personal stories in particular highlight the tenacity, determination and courage of individuals of all ages who are managing their illness or have overcome their illness and its incumbent difficulties. They also reveal the innate human capacity to accept and adapt to change and step forward towards a new life!

These experiences are invaluable and provide readers with an insight into the journeys of others towards a colostomy, and thereafter 'living with a colostomy'. Each is unique and all have much to pass on to new and experienced colostomates, families, carers and those who are involved in stoma care.

What amazing people you are – all individual, all unique!

Chatting to a very recent colostomate after contact via email. She told me that when she first woke up after her operation she found it difficult to look at her stoma or accept it. Her mind was made up, her life was over. She also said her stoma care nurse was superb, very kind and supportive. However, she felt it wasn't enough for her. Her stoma care nurse gave her a few issues of Tidings to read and this is what she said, "The more I read the more I realised I was not alone! I would be able to live my life just like everyone else, I felt so much better from that point on."

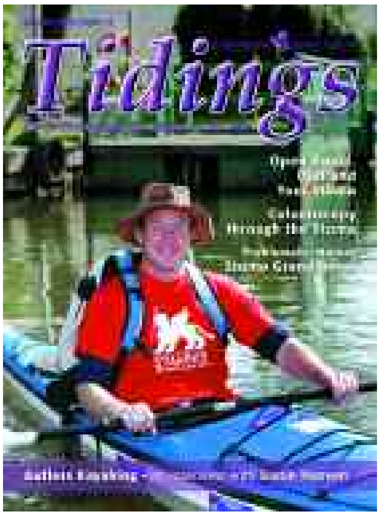
The power of the written word expressing YOUR experiences in Tidings can change how people feel about themselves; it can also change their perceptions of their newfound circumstances and lead to an increase in confidence. The above quote is testament that YOUR input makes a real difference.

I would like to say a huge thank you to that particular stoma care nurse. To all the Stoma Care Departments and to the individual stoma care and colorectal nurses that give Tidings to their patients – Please keep doing so it is much appreciated!

On behalf of the Editorial team enjoy this bumper 60 page issue of Tidings and please don't forget to send back the Tidings Feedback Questionnaire. I encourage YOU all to get involved with Tidings...YOU make it what it is...YOUR Magazine!

Jane

Email:
editor@colostomyassociation.org.uk



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

Front cover picture features Justin Hansen - Gutless Kayaking
Courtesy of Justin and Victoria Hansen

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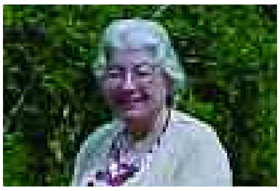
Tidings is YOUR Magazine...

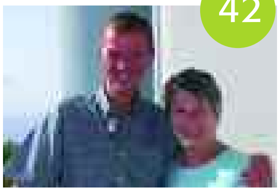
Tidings Magazine:
The views expressed by the contributors are not necessarily those of the Colostomy Association. Great care has been taken to ensure accuracy, but the Colostomy Association cannot accept responsibility for errors or omissions.

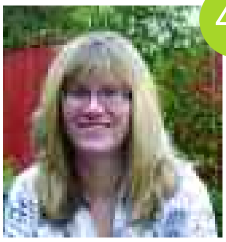
Disclaimer:
The display, description or demonstration of products and services or the inclusion of advertisements, inserts and samples within Tidings Magazine does not constitute an endorsement or recommendation of these products and services by the Colostomy Association.

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 story please get in touch.

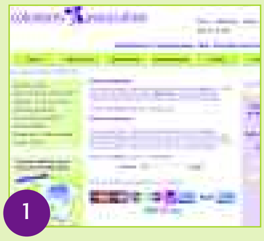






Don't delay... Donate Online today!

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



1

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

JustGiving 2

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

colostomy association

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 Winter Edition advert booking by 22nd October advert copy by 5th November publication January 2011

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

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

Colostomy Association attends ACPGBI 29-30th June 2010

The Association of Coloproctology of Great Britain and Ireland (ACPGBI) Annual Meeting was held this year at the Bournemouth International Centre (BIC). The event was well attended and offered delegates the opportunity to catch up with their peers as well as latest the information on medicines, surgical techniques and equipment.

During the three days the Scientific Programme covered discussions on controversies, evidence-based lectures, symposia, consultants' corners and short papers.

World experts from Canada, USA, Spain and Holland were among the delegates. Sessions from the Dukes' Club and Nurses Forum added an educational and entertaining flavour to the programme. For the first time a Multidisciplinary Team (MDT) corner was in action answering delegates' queries.

The event was attended by...
Sue Hatton – Executive Trustee
Richard Bray – General Manager
Jane Wood – Tidings Editor
Ian Daniels FRCS our new Vice President visited the CA stand and chatted about about potential new surgical techniques for Hernias.

L to R: Jane Wood - Tidings Editor, Mr Ian Daniels FRCS and Sue Hatton - Executive Trustee CA

Reasons for CA attendance...

- To raise awareness
- Increase education and understanding about 'living with a colostomy'.
- Knowledge gathering for the CA
- Change perceptions of patient support groups
- Continuity of networking/alliance building with significant others
- Send clear messages to those who can affect change

Outcome...

Information gathered from this meeting of specialists - provided the CA with various points and topics for further discussion and action.

Paying for Parking at Hospitals...would you like it stopped?

In a recent Good Housekeeping magazine there was an excellent article on Paying for Parking at Hospitals. Do you feel strongly about paying for hospital parking, if so contact the Editor with your comments. You can learn more by visiting the website below...

Visit: www.allaboutyou.com/lifestyle/Good-Housekeeping-Hospital-Car-Parking-Campaign/event

Is bowel cleansing oral medicine leaving a nasty taste in YOUR mouth...

If the answer is Yes! It shouldn't be! Oral medicine prior to diagnostic procedure e.g. colonoscopy doesn't have to be unpleasant, cordial can be added to taste with the exception of blackcurrant.

Accessible loos?

More and more areas are doing away with 'disabled loos' and making them Mother and Child...not really suitable for Ostomates. I think that Councils need a wake-up call and who better to do it - than our members. What do you think?

Talking about...
The Good Digestion Show

The Good Digestion Show, incorporating Stoma Central, is an exciting new exhibition bringing together all matters relating to digestion, from food intolerances and dietary choices to those with digestive disorders and stomas. Being held at Exec, on the East of England Showground, Peterborough on 24th & 25th June 2011, the exhibition will showcase all the different appliances and services, as well as clothing. The show has a seminar theatre with quality presentations running throughout and celebrity chefs Lesley Waters and Antony Worrall Thompson will be sizzling in the kitchen!

For more information and to register for tickets, visit www.thegooddigestionshow.co.uk

Helpful Ostomy Support Groups & Organisations...

- IA The Ileostomy and Internal Pouch Support Group
  Freephone: 0800 0184 724
  www.iasupport.org
- UA Urostomy Association
  Tel: 01889 563191
  www.urostomyassociation.org.uk
- IOA International Ostomy Association
  www.ostomyinternational.org
- Gay Ostomates
  Email: brian@gayostomates.org
  www.gayostomates.org
- Stomadata & Stomafr
  www.stomadata.com
  www.stoma.fr
- Macmillan Cancer Support
  Tel: 0808 808 00 00
  Mon - Fri: 9am - 8pm
  www.macmillan.org.uk
- 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
- Bowel Cancer UK
  Tel: 020 7381 9711
  Email: admin@bowelcanceruk.org.uk
  Web: www.bowelcanceruk.org.uk
- Beating Bowel Cancer UK
  Tel: 08450 719300 (Lo Call rate)
  Web: www.beatingbowelcancer.org

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 8,000+ 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: 0118 939 1537 for an application form.

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

New from RADAR - coming soon...
National Key Scheme Guide 2010
Pre-order Price: £9.49

Supporting YOU...

The Colostomy Association provides FREE support literature - covering a wide range of topics - written by medical professionals and colostomates. We are currently working on several new additions to our literature - Colonoscopy through the Stoma, Hernias and a Carers booklet.

Did YOU know that the Colostomy Association provides a patient's going home from hospital pack...if you would like more information about what is included in the pack - contact Head Office on 0118 939 1537

To obtain any of the literature listed here - simply write in, call or email your request to arrange delivery of the leaflets and booklets you require.

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

Email:
cass@colostomyassociation.org.uk

Our literature is available to download from our website. Just complete the online registration process and the literature will be available for you to download to your computer.

Visit:
www.colostomyassociation.org.uk

Tidings Magazine:
- A4 56 page Quarterly magazine Written by colostomates - dedicated to colostomates, their families and carers

Stoma Care Management:
- Living with a Colostomy
- An Introduction to Irrigation

Health:
- Healthy Eating
- About Rectal Discharge
- About Stoma Reversal

Travel:
- Travel Advice
- Travel Certificate - Europe
- Travel Certificate - Other

For Children:
- Sam has a Stoma (Children's storytime colouring book)

Raising Awareness for CA:
- One to One leaflet
- About the CA

Factsheets
- Deodorants
- Insurance for Ostomates
- Magazines for Ostomates
- Pouch/Bag Covers
- Manufacturers of Stoma Products
- Rectal Pain
- Spare Ostomy Supply Collection
- Suppliers of Stoma Products
- Support garments for Ostomates
- Swimwear
- Trousers
- Underwear
- Useful Organisations
- Websites for Young Colostomates

NON-CYTOTOXIC
Won't harm even sensitive skin
Stings Protection
LBF
No Sting Skin Barrier
30 Wipes

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

Courtesy of South Devon Healthcare Foundation Trust

The Colostomy Association welcomes... Sophie Medlin, who will be writing regular articles for Tidings. Sophie has a BSc in Dietetics from Plymouth University. Her first post was as a dietitian at Birmingham Hartlands Hospital followed by a specialist post at Poole Hospital in Dorset. She has recently taken up a position as Colorectal and Nutrition Support Specialist Dietitian at Torbay Hospital, South Devon Healthcare NHS Foundation Trust, where she works closely with the Stoma Care Department.

Diet and Your Stoma...

Many people with a new stoma find getting established back on their normal diet a struggle, particularly in the early stages. This is probably due to the unpredictability of new stomas and the period of adjustment needed to get used to the function of the stoma. It is very important to be aware that, in the majority of cases, people with stomas can return to their usual eating and drinking habits very quickly after their surgery.

New colostomies usually work within 2-5 days and the output is likely to be watery at first, settling to between 200-600mls daily of semi solid stool. A new ileostomy will start working within 24 hours and the output during the first week can be expected to be watery and around 1200mls per day. Over the next couple of weeks, ileostomy output usually decreases to around 600-1000ml per day and the stool becomes porridge-like in consistency.

With both colostomies and ileostomies, the introduction of solid food helps the gut to begin to work as normal and allows the stool to thicken and become less watery. It is important to eat as well as possible, as soon as your surgeon allows. This helps to establish a normal stoma output after the operation and will allow your body to recover.

In many hospitals, the reintroduction of food after your operation will be established as follows:

- **Stage one:** Clear fluids – black tea/coffee, jelly, clear soup, water, cordial.
- **Stage two:** Free fluids – any liquids including nutritional supplements and ice cream.
- **Stage three:** Light diet – this is very subjective but would usually include soft moist foods which are easy to digest and avoid fried, spicy and high fibre foods.
- **Stage four:** Normal diet – no restrictions.

The time period between progressing through these stages will depend on the hospital and your individual recovery.

In hospitals where an enhanced recovery programme is run, patients are encouraged to eat a light or soft diet as soon as possible after the operation. In most cases, with new stomas, this is most appropriate as there are no 'joins' in the bowel (anastomosis) and the problem in the bowel downstream of the stoma is no longer affecting digestion.

Patients with new ileostomies will lose salt from their stomas as the secretions in the small bowel are very salty. Salt is normally absorbed by the colon which is no longer in continuation with your bowel. Adding salt to your diet when you have an ileostomy will compensate for the lost salt and should not affect your blood pressure. As time progresses, your small bowel can adapt to absorb more salt and water and you can decrease the added salt in your diet. If you are concerned, speak to your doctor, specialist nurse or dietitian.

After your discharge from hospital, you should feel confident to progress to your usual diet. Many patients will be given dietary advice to avoid certain foods as they can cause watery stools or wind for example. This is very personal, however, and I would strongly recommend you avoid restricting your diet unless you find you have a specific problem for which you should seek individualised advice from your dietitian or specialist nurse. Trying to eat little and often is usually the best way to build your confidence with food and your new stoma.

It is often quoted that patients with ileostomies should be cautious with high fibre foods such as skins, peel and pips due to risk of the ileostomy 'blocking'. However, unless you have been told you have strictures or adhesions in your bowel, this is not necessary. If you are unsure, please ask a member of your healthcare team.

Healthy Eating with your Stoma...

Getting the balance right with your diet is as important for you as it is for the rest of the population. Following your surgery and if you have been ill, it is even more important that you eat well to allow for a full recovery.

Many patients with stomas find that getting their recommended '5-a-day' difficult due to the high fibre content of fruit and vegetables. If you have this problem, below are some tips for increasing your fruit and vegetable intake whilst avoiding undesirable side effects:

- Try peeling your fruit and vegetables to reduce the fibre content.

- Try fruit smoothies such as blended strawberry and banana with a little milk or yogurt.

- Cook your vegetables well and try steaming which helps vegetables to retain their water soluble vitamins better than boiling.

- Choose soft fruit which is well ripened: nectarines, peaches, melons and mangoes, for example, are well tolerated by most people.

- Try vegetable juice for a nutritious vitamin boost.

- If you have an ileostomy, add salt to your vegetables (including vegetable juice!) to help you absorb the liquid components more readily.

If you feel that you cannot eat as many fruit and vegetables as you need, it is worth speaking to a health care professional about starting a good quality vitamin and mineral supplement.

The last part of the small bowel (terminal ileum), absorbs vitamin B12, so if you have had your terminal ileum removed you may require three monthly vitamin B12 injections. If you think this applies to you, speak to your doctor, nurse or dietitian for further information. Vitamin B12 deficiency can make you feel tired and low in mood so it is worth pursuing this if you are concerned.

Please bear in mind that all the information in this article is general and if you have been advised differently by your nurse, doctor or dietitian, their individualised advice should always be followed.

Sophie Medlin BSc RD

Your diet questions answered...

Q: *I manage my colostomy by irrigation. Does this mean that I need to take vitamin or mineral supplements?*

A: If you are irrigating your colostomy, it is unlikely you will require vitamin and mineral supplementation as the majority of vitamins and minerals are absorbed higher up in the small bowel. Providing you are only irrigating once per day, the vitamins and minerals absorbed in the large bowel should have adequate time in contact with the bowel wall to be absorbed.

Editors Comment

If you have any topics you would like Sophie to cover or any questions you would like answered:

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

or Email:
associate-editor
@colostomyassociation.org.uk


AbsorbaGel

Colostomy Association Open Day 2010

Reaching out • Building awareness • Moving forward

Venue: Heritage Motor Centre - Gaydon - Warwickshire CV35 0BJ
Date: Saturday 16th October 2010
Time: 10:00am - 3:00pm

A very special Open Day Event...will celebrate the Colostomy Association achieving five years as an independent self-funding, successful charity providing support for all ostomates...

We are delighted to announce that both our President Professor Bill Heald OBE and newly invited Vice-President Mr. Ian Daniels FCRS will be attending our Open Day. As will the National Patient Associations represented by Mrs Anne Demick - Ileostomy Association and Mrs Hazel Pixley - Urostomy Association.

The Colostomy Association is very proud of its achievements to date and intends that this day brings together all those involved with stoma care - fellow ostomates, healthcare professionals, national and local support groups, manufacturers and suppliers. The event will also provide a platform for some excellent speakers - presentations on the day will reflect a positive outlook on 'living with a colostomy'.

Ultimately, we hope everyone will take away great benefits from attending this event; improved knowledge of their stoma and its care, a greater awareness of stoma care products and accessories, plus an increased confidence and a sense of belonging to a charity which is there to encourage, support and reassure. The event will open at 10:00am and after registration and refreshments will start off with an introduction from Sue Hatton - Executive Trustee, Colostomy Association. Mr. Ian Daniels FRCS - Vice President, Consultant General and Colorectal Surgeon, Royal Devon and Exeter Hospital will then give a seminar about Hernias - Cause and Treatment. Julie Bastin, Co-Founder of Breakaway will follow with an outline of the work of this important children's charity.

After a break for refreshments, Glynn Davies MP for Montgomeryshire will present his view of an Ostomate in Parliament followed by Siobhan Crowther of Lynn's Bowel Cancer Campaign who will discuss 'The importance of Screening'. We then have a presentation from Vanessa Denvir, CA volunteer, giving her view of staying positive - 'living with a colostomy' and will include details of her appearance on Channel 4's 'Embarrassing Bodies'.

Monty Taylor - Chairman of the Colostomy Association will bring the event to a close at approximately 3.00pm.

Manufactures and suppliers of stoma care products will be fully represented at this event, attendees will be able to view the stands throughout the day. We will also have 'Specialist Discussion Areas' available for attendees to ask questions about - irrigation, exercise and keeping fit and travel and insurance.

The Heritage Motor Centre is home to the world's largest collection of historic British cars.

Those attending this Open Day will have FREE access to the Motor Centre throughout the day until close at 5.00pm.

For more information contact:
Richard Bray - General Manager
Email: richard.bray@colostomyassociation.org.uk
or contact head Office on:
0118 939 1537 for more information.

Update on new stoma care products and services

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

Comfizz Cater for Children Junior Support Wear

Children can now enjoy all the benefits of wearing Comfizz modern, functional support wear. No need to worry about PE at school, or going shopping and using the changing rooms or even swimming. Comfizz soft flexible garments will hold everything securely in place, allowing you to forget about your stoma and get on with enjoying life to the full.

Comfizz
Innovative Medical & Performance Clothing

Junior Support Wear range...NOW available on prescription...

Girls Briefs

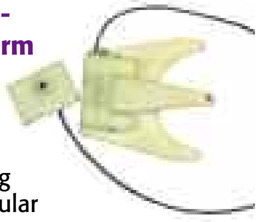
Unisex Boxers

Unisex Waistband

Available in pink for the girls and smart grey for the boys
also available in black, white, or neutral.

For further information on our children's range and adult range please contact us for a Brochure. Email: lorraine@comfizz.com or Tel: 01757 229 53.

Colostomate - Robin Rhodes - designs 'Stomalarm' - the alarm can be used at night and senses stoma activity...



About three years ago Robin Rhodes, had a colostomy following emergency surgery due to diverticular abscesses, a complication of myeloma treatment. Following numerous episodes of overfilling of the bag during sleep, he realised that some kind of alarm was needed to avoid the leakage that this caused, the ensuing laundry problems and the overall distress.

As no alarm was available, Robin being a professional Design Engineer, decided to rectify this situation. The resulting device named Stomalarm senses stoma activity and wakens the user by means of an audible alarm, allowing remedial action to be taken.

Robin is under the care of the Stoma Nurses at The South Warwickshire Hospital who are enthusiastic about this innovative development. The current version has been tested and found to be effective and is now being produced in small quantities by his company. Limited market research has indicated that a substantial percentage of ostomates/ileostomates would benefit from this.

The device is now in limited supply. Robin will be at the Gaydon Open day to demonstrate his product. For more details and how to purchase please visit: www.stomalarm.co.uk

CuiWear launches New Products... for Hernia Support

CUI are pleased to announce the launch of several new products. These hernia support Girdles and Belts (Patent pending) have been designed by CUI UK based design team drawing upon its extensive design and practical knowledge of Hernias.

In collaboration with stoma clinics this new range of bespoke support wear has been trialled for the past few months. The response from the stoma nurses has been overwhelmingly positive.

The **NEW Fulcionel Girdles and Belts** are suitable for Ostomates with large, prolapsed or unusual hernias. They help to reduce dragging sensations and minimise discomfort. In addition the construction of the patented "cupping" system together with unique lining method helps to prevent irritation around the sensitive area.

There are a large number of ostomates with unusual hernias who cannot undergo medical treatment for various reasons. A bespoke service from CUI can help to provide support for any shape and size of hernia. See advert on page 51.

CuiWear have dedicated customer services team available on freephone 0800 279 2050 to offer advice and guidance.

Some leaks are big...some leaks are small...

...but some leaks don't *have* to happen at all!

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- Ideal for peristomal skin that has crevices, fistulas or scar tissue that make the skin surrounding the stoma site uneven.
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- Hydrocolloid flange extensions
- Provide additional adhesion where it's needed
- Increase pouch wear time
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- Reduce peristomal skin irritation
- Suitable for use with all hydrocolloid flanges

Patent number 2397230

HydroFrame®

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1017/0109

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 19....**
Thank you!

Dear Editor
On July 1st, I had my 90th Birthday party, which was attended by my family and friends. I asked for no presents, but suggested they may like to make a donation to the Colostomy Association. I am delighted to say they did! Please accept a donation of £255. I enjoy reading Tidings and have learnt much from the information provided.
Yours sincerely
MT

Thank you everyone for your kind donations

Dear Sir
I enclose a donation of £200. Members of Mynydd Cynffig WI did a sponsored walk to raise funds for your organisation, which has provided support to two of our members.
Yours sincerely
EV

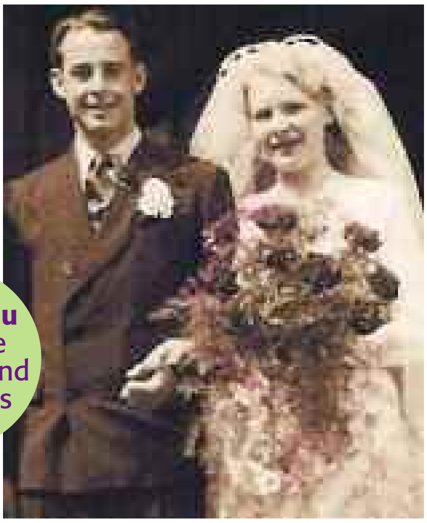
Dear All
We recently had an anniversary celebration and £50 was donated to the charity of our choice. We therefore enclose this donation and know it will be put to good use.
Keep up the good work.
Yours sincerely
C and D Braund

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

In Memory...

Mrs Myra Fletcher	£404.30
Mrs Nelda Bradbury	£ 30.00
Audrey Hart	£ 80.00

Thank you



Dear Tidings
We got married on the 29th July 1950 and recently celebrated our Diamond Wedding Anniversary. The wedding was held at St. Margaret's Church in East Wellow, near Romsey where Florence Nightingale was buried. To celebrate we had a get together with all our family and friends. We requested 'no presents' but suggested donations, to go to the Colostomy Association. I delighted to enclose a donation of £225. I hope that this will help to give support to other colostomates, their families and carers.
Yours sincerely
J and R Haken

Dear Sir/Madam
My friend and I held a coffee morning in aid of the Association in May and I have pleasure in enclosing a donation of £305, which we trust you will find very useful.
Yours faithfully
RG

500 Club - June Draw

Mr L Sutcliffe	£326.00
Mr M McGowan	£163.00
Mr G Gammon	£163.00
Mr P Jesshope	£163.00
Mrs M R Green	£ 81.50
Miss J Matthew	£ 81.50
Mrs M Graham	£ 81.50
Mrs E M Woodhouse	£ 40.75
Mrs E Payne	£ 40.75
Mr R Mansfield	£ 40.75
Mr A Williams	£ 20.38
Mr P Day	£ 20.38
Miss R Kealy	£ 20.38

Dear CA
Recently, on a very wet and windy evening, members of Lampeter Inner Wheel held a BBQ in aid of the Colostomy Association. In spite of the fact that there are just nine members and the inclement weather we raised £300. Many thanks are due to 'Rotary Husbands' who stood bravely in the rain and cooked the food!
MJ (Mrs)

Dear Sir/Madam
On behalf of the Church Council, I have pleasure in enclosing a donation to the value of £100 being a contribution towards the ongoing work of your Association.
Truro Methodist Church

Other kind donations received...

- Royal Victoria Infirmary Open Day raffle raised £115
- Rockwell Collins UK Ltd raised £50
- Wrexham Ostomy Friendship Group raised £15

Can YOU help?...We want YOUR old or unwanted mobile phones, please! Every phone returned to the Recycling Appeal by YOU on our behalf means YOU are helping us to raise funds - as the proceeds come back to Colostomy Association. Contact us: 0118 939 1537 or email: cass@colostomyassociation.org.uk and ask for YOUR FREEPOST envelope today! Then place your old or unwanted phones into the envelope, seal and drop in the post!

Did YOU know... The **Colostomy Association** has teamed up with **Charity Flowers - www.charityflowers.co.uk** to receive 15% of any orders placed with them - **it's a winning combination - two gifts in one!**

The **Colostomy Association** would like to take this opportunity to say a **BIG THANK YOU** to **everyone who donates and fundraises on our behalf.** We try to publish as many letters as possible - to those of you not mentioned here - you are not forgotten - we would not be here without you **- So, PLEASE keep up the GOOD WORK!**

Department of Health Consultation - May 2010

Arrangements under Part IX of the Drug Tariff for the provision of stoma and incontinence appliances and related services to Primary Care...

An overview of the new arrangements under Part IX of the Drug Tariff for the provision of stoma and urology appliances – and related services – in primary care has been published on the Department of Health website at:

http://www.dh.gov.uk/en/Consultations/Responsestoconsultations/DH_097226

Some of the key points are:

- The new arrangements were implemented on 1 April 2010.
- These new arrangements do not affect dispensing GPs, who will continue as before.
- Dispensing Appliance Contractors (DACs) and Pharmacy Contractors (PCs) who dispense prescriptions can choose to offer either Essential Services or Essential Services plus either both or one of the Advanced Services.
- Essential services that must be provided include a repeat dispensing service, appropriate advice, a home delivery service and a supply of wipes and disposal bags.
- There is also a requirement to provide urgent supplies, prior to receipt of a prescription, provided the prescriber undertakes to provide a prescription within 72 hours.
- Advanced services include stoma appliance customisation and appliance use reviews (AURs).

The ESSENCE of Service Provision

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 (AURs). 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.

- AURs must be conducted by a specialist nurse working on behalf of the DAC or PC or by a pharmacist, either in the home of the patient or at the DAC or PC premises, where there must be a specially designated area for confidential consultation, away from areas to which the public have access. At all times, these specialists must maintain close contact with the NHS healthcare professional looking after the patient and also their General Practitioner and advise of any proposed changes. The request for an AUR must be prompted by the patient and not the contractor.

- All contractors must be able to describe to patients how the electronic prescription service will work when it is available

- The new arrangements have been put in place to ensure that DACs operate within a similar clinical governance framework to PCs and that PCs offer a similar level of service as the DACs.

The Department of Health lists the key aims as:

- Maintain – and where applicable – improve patient care;
- Ensure equitable payment to DACs and PCs for the provision of equivalent services;
- Achieve transparency between what is paid for services and what is reimbursed for items.

- The detail is in the remuneration and reimbursement arrangements that apply to the contractors (DAC & PC).

Kind thanks to
Anne Demick IA
for contributing this article

A Colostomate Comments...

written by **Rosemary Brierley - Associate Editor**

A regular column from a colostomate's perspective, which raises, researches and discusses issues associated with living with a colostomy. If you would like 'Tidings' to focus on a particular topic or issue that affects you day to day or would like to comment, please write in or email: associate-editor@colostomy association.org.uk. We look forward to hearing from you.

"Is a colostomy classed as a disability?"

This question often comes up on the CA helpline and at open days. The reason people ask will vary. It may be because they want to know whether they are entitled to disability benefits or if they may use facilities designed for the disabled i.e. parking spaces or toilets.

Disability Benefits include Employment Support Allowance (ESA), which used to be called Incapacity Benefit, and Disability Living Allowance for people under 65, or Attendance Allowance for those of 65 and over.

The Disability Rights Handbook states that ESA is for people assessed as having a limited capability for work. This is determined by the ability to perform physical functions classified under eleven activities including walking, standing & sitting, manual dexterity, hearing, vision etc. A stoma comes under the continence section. On its own a stoma only counts if you are unable to affix, remove or empty your stoma appliance without help from another person, or without causing leakage of contents. However, if in addition to a colostomy or ileostomy, you also have problems with urinary incontinence you may qualify. Some ostomates may receive ESA if other physical (or mental) functions are impaired for reasons either related or unrelated to their stoma.

To qualify for Disability Living Allowance (Care Component) or Attendance Allowance you must be so severely disabled, physically or mentally, that you require, from another person, frequent attention in connection with your bodily functions.

So it seems that it is not the stoma which determines whether a person is entitled to disability benefits, but how the stoma and/or other medical problems affect that person's life. Does it affect your ability to work? Do you need help with changing an appliance on a regular basis?

An abdominal stoma is on the WaterSure scheme's list of medical conditions which require the use of significant additional water. However, it is only if your water supply is metered and there is someone in the household who receives an income-based benefit or tax credit that WaterSure may be able to help by putting a limit on the amount you pay in water and sewage charges.

Parking Permits and Toilets are topics frequently mentioned on the helpline. The Department of Transport's leaflet "Can I get a Blue Badge" states that to qualify for a disabled parking permit you must have a permanent and substantial disability which means you cannot walk or which makes walking very difficult. So it seems that it is mobility that is the sole criteria here.

However, all of us who have a stoma have the right to use a Disabled Toilet (now much more appropriately called an Accessible Toilet). The extra space, washbasin and disposal facilities make pouch changing so much easier. We are also entitled to apply for a RADAR key.

Every ostomate is different, a fact that is evident from the letters and stories that the CA receives and prints in Tidings.

On the one hand we read about people who after stoma surgery have returned to their former life and employment and even run marathons or travel the world. They have never considered themselves - or would want other people to label them as - disabled.

On the other hand for some a colostomy is not a cure for the original medical condition. Some ostomates may have had large sections of bowel removed or may develop complications during or following surgery which lead to ongoing problems. A stoma may be formed to improve the quality of life for those with existing disabilities i.e. spinal injury or multiple sclerosis. There are also ostomates who qualify for disability benefits for other unrelated medical conditions e.g. heart disease, arthritis.

So it seems that the answer to the question of whether an individual with a colostomy is disabled is: 'Well, it all depends…'

For more information:

Benefit Enquiry Line
Tel: 0800 88 22 00
Email: bel-customer-services@dwp.gsi.gov.uk

Citizens Advice Bureau
(see local telephone directory)
Web:
www.citizensadvice.org.uk
www.adviceguide.org.uk

Macmillan Cancer Support
Help with checking benefits, filling in forms etc. for people with cancer.
Tel: 0808 808 00 00
Mon – Fri 9am - 8pm
Web: www.macmillan.org.uk

Leaflet: "Are you eligible for WaterSure?" available from
Consumer Council for Water
Tel: 0845 039 2837
Web: www.ccwater.org.uk

Leaflet: "Can I get a Blue Badge?"
available from the
Department of Transport
Tel: 0300 123 1102
Web: www.mobility-unit.dft.gov.uk

Reference:
Disability Rights Handbook 35th Edition
April 2010 – April 2011
Published by DisabilityAlliance
IBSN 978-1-903335-47-5
Chapters 3,4,9 &10

"Cruising - disposing of flushable pouches...aboard ship..."

In the last issue of Tidings we published three letters from ostomates who told us how they had successfully disposed of the inner liner of flushable colostomy bags down the toilet on cruise ships but two of them stressed it was very important that the flange is removed first and disposed of separately in the waste bin in the en-suite. However, since then we have received the following letter and e-mail from readers which we would like to bring to your attention.

Dear Associate Editor
I recently wrote to the Chief Engineer of the P & O cruise ship Oriana asking whether it would be safe to flush Freestyle Vie (flushable) pouches down the lavatories on board his ship. I hope the enclosed reply will be helpful to your readers.

Kind regards
Pauline

P.S. I am also sending a copy of the reply to the manufacturers of Freestyle Vie flushable pouches.

P & O Cruises
Re Freestyle Vie flushable pouches

Thank you for your letter which was passed on to Oriana's Chief Engineer. Regrettably he has advised me that we cannot allow any item other than human waste and our ship toilet paper into the sanitary system on board due to the extremely narrow pipework in the vacuum system. Each toilet has a snag ring at the back on which the bag would be caught initially and this would block not only your toilet but all the others (approx 25) on your section with flooding being the result. Added to this we have a bio-friendly system and the addition of chemicals in any shape or form would upset the delicate balance in which the live bacteria would work.

We are sorry we cannot be more accommodating with your request, however, the risk involved with flushing other products is one that the ship feels is too great.

I would like to take this opportunity to wish you an enjoyable cruise.

Yours sincerely
Medical Processor
Fleet Medical Department

E-mail
Subject: Cruise ship toilets
On our recent cruise due to problems occurring in the toilet system the Captain stated quite unequivocally over the address system "If you haven't eaten or drunk it first, do not flush it down the toilet." I personally use the sanitary bags provided for ladies which my wife deposits in the bin provided in the "Ladies". Perhaps these bins should be also provided in the "Gents" everywhere not just on ships. Thank you for a very useful magazine, even though after seven years I am still fortunate to have very few problems with my stoma.

C.S. (Mr)

Alternatively, to dispose of used pouches you can ask the ship's medical centre to supply a yellow medical waste bag which will be regularly and discreetly collected from your cabin. If you normally empty your pouch you can seal it inside a disposal bag and leave it in the bin in the en-suite which will be emptied twice a day.

Editors comment
If you have any issues you would like raised in this column please e-mail:
associate-editor@colostomyassociation.org.uk

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

Be Prepared...

Organising a holiday or business trip - whether it's at home or abroad - can be an exciting and sometimes exhausting process! Planning ahead can prevent the prospective traveller from experiencing any last minute hitches. Air travel is often of real concern to the ostomate and the CA receives many travel related enquiries to their helpline. The following are a series of helpful hints and tips for those who fly away to distant shores...

- Always carry a letter from your Doctor stating that you need to carry your supplies in your hand baggage (a Doctor's letter may attract a fee).

- Ensure you have a Travel Certificate that states you have a colostomy/ stoma, available from the CA or your supplier. Carry the Travel Certificate and Doctor's letter on your person – so that they are readily available should you be questioned about your colostomy during a body search.

- Be sure to take with you the telephone numbers of your supplier – in case of an emergency and the need to obtain fresh supplies.

- Carry a prescription detailing your supplies. This proves your items are medical plus gives information if you need to purchase or send for supplies.

- Be prepared to carry your supplies of pouches and flanges in your hand baggage. This should be possible – even for a very long stay – as cabin baggage on most airlines allows a bag of 22in (56cm) tall, 17.7in (45cm) wide and 10in (25cm) deep.

- Pack at least twice the amount of pouches and flanges for the period that you will be away. This allows for accidents and tummy upsets, or for other activities such as swimming which may require more pouch changes than usual. Don't forget to pack the same for other necessary items for your pouch change routine.

- Unpack your supplies from their boxes and re-pack in transparent bags, placing a prescription on top of the pouches. This ensures that anyone examining the items has no need to handle them to check what they are.

- Any liquid you may wish to carry on board must be less than 100ml and be carried in a transparent resealable bag ready for examination. Scissors must be placed in your hold luggage. Take pre-cut pouches if necessary.

- Always include a small pouch change kit (in a transparent resealable bag) in your hand baggage. It should contain a couple of clean pouches, wet wipes and disposal bags, so that if you need to change during the flight, you can!

- In case of a body search and a request to see your stoma/pouch (in a private search area) always carry a clean pouch plus disposal bag on your person, in a pocket – just in case!

- Before going through the security system try to have a clean bag – this does not show up so clearly on the screens of the new body scanners.

- Avoid wearing anything that might set off the alarms, jewellery etc; so you get a clear walk through.

NB: It is not always necessary to inform your airline that you are an ostomate. However, if you prefer to advise them, then contact the airlines customer service team, and they will make a note against your reservation. If you require an aisle seat ask them for their help to secure one.

written by
Jackie Dudley
Trustee

Irrigation and you...

Sue Hatton Executive Trustee writes...it has been over a year since Tidings began highlighting irrigation for colostomates. The response has been amazing - we are delighted to hear that some of you are now irrigating due to reading Tidings. Thank you all for your valuable contributions please do keep them coming.

There was some dissention amongst the editorial team that my Irrigation page was taking up space, after all 'only 3% of Colostomates irrigate'. This my point, why do only 3% of Colostomates irrigate? Are they given the choice? Did their surgeon ask them prior to surgery, 'If you were given an option of washing out your bowel each day and then not having to use the bag/pouch would you like to know more?' Some surgeons seem to be uninterested in the Ostomate as a person with a life after the removal of the diseased colon, they see us as an interesting challenge to remove the offending part of the organ but do not consider how we will then cope with a stoma.

Our stoma nurses are our guardian angels. They tell us what we should do and we hang on their every word. If your stoma nurse says she has discussed your life as a colostomate with the surgeon and that your stoma has been formed so that you can wash out your bowel each day (or every 2 days), and if you think your home life could accommodate you using a loo for up to an hour a day, then we irrigators are unanimous in agreeing that this is a great option. If you decide it is not for you, it's YOUR choice. My concern is that YOU are being given a CHOICE.

I have been irrigating for 12 years. Sadly my body has changed shape and the trim woman that emerged after surgery, chemotherapy and radiotherapy has grown as I become more sedentary! I cannot wear the plug as most proficient irrigators do, I prefer to play safe and wear a bag/pouch. Over the years, I have been used to my 'guts' playing up when I am out of my comfort zone and the bag (the original bag that was recommended to me by my stoma nurse!) has not played fair and I have felt that nasty warm mess trickle, or sometimes gush down my nether regions! I have persisted and slapped it on and held my breath, great when I'm at home, but a nightmare if I am away.

But, I was given a free sample of bags (I have to be impartial and cannot recommend a certain product by name!), but they stick to this wrinkled, creased, stretch marked tummy and they stay in place! When I feel that ghastly horrid moment that I know is a huge bowel movement and sweat sits on my upper lip, I am safe – because it all goes into this wonderful bag, no smell, no obvious sign that I have a balloon on my belly AND most amazingly, if I am somewhere that I would rather not carry a pint of poo around, I can easily dispose of the bag.

So another tip, do not keep with the same products if you feel they are letting you down. Your body changes as you get older, so the adhesive on the pouch does not always stick and you may need to build around the stoma. Your stoma nurse can advise you, all you have to do is to book a review. The carelines of stoma care appliance suppliers are also very helpful and a port of call if you want to try something new.

Richard Farrow contacted me after the last issue to complain that I had not included enough of his advice on constructing his prototype sleeve. If you would like to discuss this with him, you can obtain his number from head office or will pass your number onto him. The same advice goes for anyone wanting to contact me! You can always send an email and the girls will forward your comments to me.

Bob Buckley wrote back following my queries about reusing irrigation sleeves in the last issue. He quotes from a declaration leaflet in his box of supplies which states;
According to the European medical device directive as amended in 2007, we should inform you that, "Reuse of this single use product may create a potential risk to the user. Repossessing, cleaning, disinfection and sterilisation may compromise product characteristics which in turn create an additional risk of physical harm to or infection of the patient"

This was also picked up by Roger Ashford who gave his opinion on 'should we pay if we do not reuse our sleeves'. Prior to irrigating he used two or three pouches a day, whereas now he uses one sleeve and one stoma cap. Roger has suggested a possible cost saving to the NHS of £1,300 per year – he also suggests they should be paying him! Roger sterilises his equipment once a week using Milton tablets, which he says reduces the amount of mould build up in the corners of the bag and in the tube, but it does not eliminate it entirely; he believes that the Milton also degrades the material over time (it seems to get yellowish and less flexible). Roger asks "Does anyone know of a more effective sterilisation product?" He replaces the bag every six months.

Janet Bradley uses B.Braun's water container, tubes, cone and valve and Dansac sleeves. She tried Coloplast, but does not like the belt and sleeve system and comments that the water container does split. She has spoken with a representative from Coloplast who told her that was 'just the way it was'! She was advised to wash it out with bleach. Understandably Janet's reaction was that there was no way she would put water through her stoma via a tube that had been soaked in a bleach solution. She states that B.Braun's equipment lasts much longer and can be taken apart. Individual pieces can be replaced, thereby saving money.

Shirley uses Dansac sleeves as they stick to her skin and she would never reuse a sleeve. She steeps her

equipment in Milton once a month and renews her bag when the equipment starts to fail.

I would also like to thank Mr David Colsell for his letter telling me that he has been irrigating since the early 1970s, he irrigates every 48hrs – this will always last to within a few hours of the next operation. He writes 'I can say, without doubt, irrigating is the best, most sensible thing I have ever done (except to marry my wife, in case she reads this)!!'

Paul George tells me that he did not know about irrigation until he read our page in Tidings. He made an appointment to see his stoma nurse Sister Paula Brayford at the Royal Shrewsbury Hospital. He writes' Sister Brayford was very helpful, professional and caring. From that day on I have not looked back. I now feel I can go out again with no problems, the first time in several years after spending just 45 minutes a day irrigating. 'Life Changing! Thank you Tidings for your help!!'

In response to my cry for help having forgotten my base plate, Adrian Davis emailed in to tell us about an entertaining little diversion during his enforced stay away from home courtesy of the Icelandic Volcano.

He had taken lots of spare bags and wipes, in case of an upset, but didn't expect to spend any more than two days away from home to allow for the odd cancelled flight or bad weather, so he only took one extra sleeve that could be rinsed if absolutely necessary. (The second rinse never gets rid of the pong!) Here he tells us how to improvise to create a Volcanic Irrigation Sleeve!

"As I didn't want to abandon irrigation altogether, I tried improvising with disposal bags, which does work to some extent, but tends to get a bit messy. They are the wrong sort of plastic.

Instead he suggests, visit the local supermarket and buy a pack/roll of freezer bags (the 'right' sort of plastic), and both some single sided and some double sided sticky tape. Add scissors if you have forgotten your own. Trim the closed end from one bag, slip the end into another and stick all around with the single sided tape - there you have it - a sleeve well almost. It obviously has a right way up in terms of flow direction and it can be shaped using more tape if you prefer. Cut a hole of an attractive size to fit your stoma in an appropriate place on one side, not too near the top and cut an opening in the top for cone access. Then surround the hole, on the outside with a patch of double sided tape. How many strips depends on how wide the tape is, of course, but you should aim to make a patch not dissimilar to an ordinary wafer, give or take a bit. Make sure the tape is right up to the lower edge of the hole, because that is where it is most likely to leak if it does. Try to keep your fingers off the sticky outside surface if you can, especially near the middle where adhesion is most important.

Come irrigation time, apply the sleeve in the natural way, press on well and get irrigating. (Your double sided sticky tape is not as strong as wafer adhesive and may have been downgraded by accidental fingerprints).

In the absence of any commercial top closure, it is amazing what you can achieve with little pieces of sticky tape. Improvise a bit – bag to bag – bag to tum – whatever.

Nothing ventured, nothing gained. In future I will take only one additional sleeve just in case, but I will also toss in a little roll of bags and sticky tape!'

Now you all know how to make a Volcanic Irrigation Sleeve! Maybe we should keep this info as a leaflet!

Finally, Richard Allardyce wrote that he was disappointed with the lack of understanding that seems to prevail about irrigation. He went to an Open Day and of the 15 stands not one supplier had a sample on show. He says that he has tried 3 different types and none are perfect. He is disappointed that none of the representatives are interested in taking his ideas further.

May I suggest that if you know there is an Open Day and you are prepared to attend and man the Colostomy Association stand, you take a kit bag full of brand spanking new irrigating equipment, and that you are prepared to show interested colostomates how the procedure works. All I would ask is that you keep your clothes on and demonstrate over them!

I will ensure that head office has complete kits for demonstration purposes - so you can phone the office and request an irrigation kit.

Editors Comment

If you would like to share your irrigation stories or comments

write to:
Sue Hatton
Executive Trustee
Colostomy Association
2 London Court East Street
Reading RG1 4QL

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

Overcoming life's challenges... stepping out into a new life

Janet Bradley CA Volunteer and intrepid traveller takes us on her own personal journey towards a colostomy and explains how she was introduced to irrigation...

My name is Janet Bradley. I am 72 years old and have had a stoma for 13 years. In 1995, I had been living abroad with my husband for 32 years, 19 of which were in Kobe, Japan. That year I was shaken by two big earthquakes. The first was in Kobe and the second was that my husband had fallen in love with a young Japanese woman and wanted a divorce. Whilst I was making plans to return to England, my brother-in-law died of a heart attack. I came back in November 1995 and stayed with my widowed sister whilst we propped each other up.

I wanted to start a new life on my own so in April 1995, whilst I was house hunting for something permanent, I rented a flat in Henley-on-Thames. In July I found a small house for me and my dog. Shortly afterwards, one of my sisters was diagnosed with terminal breast cancer. My other sister (my twin) and I took it in turns to nurse and look after her, but after much suffering, she died in October 1996.

I picked myself up again and tried to restart my life, but I was not feeling well. I went to my GP and during repeated visits was prescribed peppermint pills and counselling. I was told it could not possibly be cancer. I finally insisted on further advice and was sent to an IBS specialist. The results were due on a Tuesday, but I suddenly received a 'phone call to come in on Monday instead. Dukes B cancer was diagnosed and the operation took place 3 days later. My consultant was very positive and said the chances of needing a stoma were 99% against. A week later I was recovering well but suddenly felt very poorly. Some days later I woke up in intensive care with my twin sister sitting next to my bed. She had been there day and night after receiving a 'phone call at 6am saying I was at death's door. She caught the first train from Devon and stayed with me for the next 3 weeks. I swear she saved my life by hauling me back from a "white light" experience when I really wanted to go.

Apparently, my operation had been successful, but the join had burst and I had septicemia. I was rushed to surgery and a stoma was formed. I went back to my room from theatre but, two hours later, I was very ill again. It was discovered that my spleen had been nicked during surgery, so it was off to theatre again to have my spleen removed. I ended up in intensive care for a week and two more weeks back in the ward. Even then, I had another scare when I suddenly started bleeding large clots from my rectum. The stump of my intestine had come unstitched so it was back for yet another op.

After a month, I had become quite lethargic and probably slightly institutionalised in hospital, but one day a lovely nurse saw my problem, helped me into a wheelchair and took me out into the sunshine and flowers. She gave me the very good advice "Take one day at a time, and do a little more each day".

When I finally got home, my twin sister stayed with me for two weeks and then I went to stay with a very good friend for another two weeks. Back at home, I took my dog for a slightly longer walk each day and became stronger and stronger. I had six months of chemo, delayed for four months until I was well enough to cope with it. In May, a friend drove me to the hospital for my last day of chemo and also arranged a surprise party with champagne and smoked salmon. Two months later I flew to LA and stayed with friends for two weeks. I was still not very strong, so we did one day sightseeing, and one day rest. Two months later, feeling brave enough, I went on a short cruise and found I could manage on my own. I contribute much of my recovery to my wonderful family and friends, and consider myself very lucky indeed to have had them there.
I started going out and about more

Some of you may remember Janet modelling at the Fashion Show - part of the CA National Conference held at Reading University in 2008...here she is beautifully decked out in pink, courtesy of John Lewis - Reading.

often, trying to be as normal as possible. One evening in October 1999, I sat next to a man at dinner, and we got on very well. He asked me if I would go out with him.
I realised very early on that I had to tell him I had a stoma, so I suggested we went for a coffee. I explained I had been very ill and had a stoma. He had no idea what I was talking about and asked "Have you had a mastectomy? When I said "No," he replied "That's all right then". He now calls me his bag lady. He has survived leaks in the bed, leaks on other people's bathroom carpet, etc, etc, and never turns a hair.

But fate hadn't quite finished with me yet. In February 2002 just as we started planning our wedding, I was diagnosed with bilateral breast cancer. Fortunately, I managed to get better in time for a beautiful May wedding with all my friends and family. We had to cut our honeymoon short for me to start a six week course of radiotherapy. I was lucky enough not to need chemotherapy so I didn't have to wear a wig at my wedding. We have just celebrated our eighth wedding anniversary.

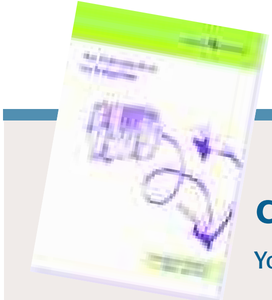
When I came out of hospital after bowel cancer, my stoma nurse visited me at home. She asked if I had everything I needed, but I had no idea of the vast range of appliances and accessories available. I thought the see through white pouch was all there was! She told me about irrigation but said I probably wouldn't like it.
I didn't think of asking for more information. My mind was not functioning very well after all the anaesthetic. Have you heard of the CRAFT Society? All of us who have had lots of anaesthetic become members for about a year. It stands for "Can't remember a flipping thing!"

What a difference a day in Reading made to me a couple of years later. I walked past a building which had a plaque saying "Colostomy Association". I went up the stairs and a whole new world opened up.
All kinds of information, pamphlets, people who understood and, best of all, "Tidings". Other people have problems too!

I was collecting supplies from my local surgery one day when the receptionist asked me why I didn't irrigate. Her husband did, and he offered to talk to me about it. We met up and, as a result, I contacted my stoma nurse and made an appointment to learn how to do it.
It was not a great experience. We sat in her office where there was a wash basin and a bucket. It is a good job not much fazes me nowadays.
I persevered and I am so pleased I did. I am not one of the lucky ones who can irrigate every second day.
I irrigate every day Monday to Friday. On Saturdays I delay until about 4 or 5pm and then have Sunday off. On weekdays, I put the kettle on first thing, make a cup of tea and retreat to the bathroom for 20 minutes.
By that time, most of the stool has evacuated and the bottom of the irrigation sleeve can be sealed with pegs. I then make breakfast, read the paper and take a shower - about 20-30 minutes. If anything else is evacuated, I rinse out the sleeve into the toilet bowl and then put on my pouch or patch. Mostly I wear a flushable pouch because my stoma has a mind of its own and I can only rely on it 99% of the time. Every now and then it will show me that I am not entirely in control.

Recently, there have been many informative articles on irrigation in Tidings. I know that irrigation is not possible for everyone and we should all have the consent of our surgeon and training from our stoma nurse. But for me, the advantages are manifold. My body image and a measure of control of bowel function have been restored.

I can do anything I did before I had a stoma – age permitting. I have taken up horse riding, Pilates, travelled to Japan, Singapore, Australia, Tasmania and various places in Europe. Since I started irrigating, I haven't need so many supplies when travelling – have extra space in my suitcase and less worry about running out of pouches. Skin allergies and leaking, pancaking, and all those other niggles are things of the past. I think I can say completely honestly "Everywhere I can hang my hook is home".



Editors Comment

You can learn more about irrigation from our leaflet - 'An Introduction to Irrigation' to obtain your copy

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Reading RG1 4QL

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Colonoscopy through the stoma... a patient's perspective

There are certain important dates in a bowel cancer colostomate's life that are a huge relief to tick off in the diary. The six month check up, the first year anniversary, then the second…

It is unbelievable to have reached the five year point, to have clear blood tests and to be considered free from cancer. Thereafter it is recommended that five yearly checks are carried out. However, if there are indications that the colon has changed, then your colorectal surgeon or gastroenterologist may suggest more frequent check ups.

These check-ups usually include a colonoscopy. This procedure is carried out by an endoscopist using a colonoscope. This is a long, thin, flexible tube about the thickness of your little finger, with a bright light at the end to examine the lining of the colon.

The human intestinal tract averages about thirty feet in length. The last five to six feet is called the colon, also known as the large intestine. Like a piece of flexible pipe, the colon is hollow with the inner surface being normally smooth. For unknown reasons, some of us grow small lumps of tissue, or polyps on the inner wall of the colon. A colonoscopy can reveal any small abnormalities and take biopsies (a tiny piece of tissue for laboratory analysis).

Whereas the colonoscope is normally passed into the colon through the anus, for colostomates it will have to be inserted through the stoma. Only one in eighty colonoscopies is carried out in this way.

Before your appointment

It is very important that you read the instructions through carefully and put into your diary the dates that you need to be aware of prior to the procedure. If you are taking medicines to thin your blood e.g. Warfarin, Clopidogrel (Plavix) or Aspirin it is imperative that you speak to your doctor or the endoscopy department to discuss whether you should stop them before your colonoscopy. If you attend for a colonoscopy and you are still taking Warfarin you will have to have an INR test and if the result indicates that your blood is too thin, you cannot have any abnormal growths removed and will have to make another appointment for another colonoscopy (and another 24 hours of taking the bowel cleanser!).

Bowel Cleansing

Now we come to the worst part! The bowel has to be clear so prior to your appointment so you will be sent a special bowel cleansing solution with easy to follow instructions. The preparation you receive: Moviprep, Picolax or Fleet will depend on your endoscopy department. Flavouring it with fruit squashes (not blackcurrant) can makes it more palatable and using a straw will help as apparently the drink will then miss the taste buds.

The instructions will also advise you what you are allowed to eat but this will depend on whether you have a morning or afternoon appointment. Usually clear soups, fluids, clear jelly (not red) and meat extract drinks are allowed at certain times prior to the procedure.

On the day before your test while you are taking the bowel cleansing solution you will be advised to stay very close to the loo!

Drainable Pouches

It is also advisable to ensure that you have a supply of drainable pouches, so that you do not have to keep peeling off the closed pouch each time it fills up. Phone your appliance provider and ask for a variety of drainable bags/pouches and make sure you have tried them out before you have your colonoscopy, to ensure the adhesive sticks and there are no leaks. For those colostomists who haven't used drainable pouches before, it helps to wash the outlet with anti bacterial solution after each opening.

Remember to take new pouches with you as you will need to change after the procedure.

At the Endoscopy Department

You will have to fill in forms and agree to the procedure which lasts for about 15 -60 minutes. However, you should be prepared to be there for up to four hours in total for preparation and recovery. It is advisable to have someone bring you and pick you up. Even if you do not elect to have the sedative, you can feel a bit fragile after the procedure.

When you put on the hospital gown, remember to have the opening to the front. The nurses may comment that the opening should be at the back, but when you point out that the colonoscopy will be carried out through the stoma they will have to admit that you are right!

In the endoscopy room you will be asked to lie on your back on the treatment couch and given a sedative by injection. Many patients remember nothing of the procedure. Sometimes the sedative can knock you out completely and the advice given by the hospital is that you do not drive, operate machinery, work or make any important decisions for 24hrs after the sedation and that a relative or friend should stay with you. You can opt not to have the sedative. This will enable you to see exactly what is in your colon and discuss with your endoscopist what is happening.

Once the colonoscope has been inserted through the stoma and into your colon, air is passed through it to give the endoscopist a clearer view. During the procedure, the consultant may want a sample of the lining of the bowel to be taken for examination in the laboratory. This is called a biopsy. Only a small piece of tissue is removed using tiny forceps and the process is painless. The endoscopist may also remove any polyps (abnormal growths of tissue) through a side channel in the colonoscope.

Polyps

There are various types of polyps:

- Non-cancerous (benign) polyps called adenomas that could potentially become cancerous and need removing
- Harmless polyps that may not need removing

What happens after a colonoscopy

You may feel pressure, bloating or cramping because of the air passed through the colonoscope during the procedure. This should pass quickly. When you put your colostomy bag back on it will fill up with flatus (wind) so it is advisable not to cover the filter and to change again, once you have finished in recovery.

In some cases the endoscopist or a member of nursing staff will discuss with you the findings and will give you a copy of the Colonoscopy report. This will also be sent to your GP. He will also advise when you should return for future colonoscopies.

For most patients, national guidelines recommend a check once every five years but if you have a particular risk of further cancers or form a lot of polyps, you may be offered check-ups every one to three years. It generally takes up to ten years for cancer to form from polyps. If the polyps have re-grown you are entitled to opt for a regular repeat procedure. It is better to have them frequently - up to once a year - to ensure the growths are removed. For genetic reasons your consultant may advise that you should have them investigated annually.

You will then be offered a cup of tea and a biscuit while you wait until the nursing staff agree that you are well enough to leave.

What are the known risks of Colonoscopy?

Endoscopists who have been specially trained and are experienced in these procedures perform colonoscopy and polyp removal. However, complications can occur and include:

- Perforation or tear through the bowel wall that could require surgery
- Bleeding from the site of biopsy or polyp removal – usually minor and stops on its own
- A reaction to the sedative injection

Although complications after colonoscopy are rare (less than 1:1000), it is important for you to recognise early signs of any possible complications. The risk of complications is higher when colonoscopy is used to apply treatment such as removal of polyps.

Contact your GP or attend the emergency dept if you notice any of the following symptoms or if you are worried:

- Severe abdominal pain
- Vomiting
- Fever and chills
- Continual bleeding and the passage of large blood clots on more than one occasion after a polyp is removed.

When will my GP and I know the results?

In many cases, the endoscopist will be able to tell you the results of the tests immediately and may be able to print the colonoscopy report for you take home. It may, however, take several days to get the results if a biopsy has been taken or polyps removed. These results will be sent to your GP or an endoscopist in the outpatient clinic or on the ward who will discuss these results with you.

Written by
Sue Hatton
Executive Trustee
Ernie Hulme
Vice Chairman
Colostomy Association

Kind thanks go to:
Dr Iain Murray, Consultant Gastroenterologist (Royal Cornwall Hospitals NHS Trust) who has assisted the Colostomy Association in producing this article, which be shortly be available in leaflet form.

Alfie's Story...

On 26th June 2008 our baby son was born six weeks early by emergency caesarean section. He weighed just 4lbs 7oz. We named him Alfie. He didn't feed very well because he was premature. I wanted to breast feed him but had to give him a bottle as well because he was struggling to suckle.

We never knew anything was wrong with Alfie until the doctors came round and asked us if he had passed his first stool. They noticed that his tummy was distended and told us that they needed to take him up to the neonatal unit. He went into an incubator and was wired up to machines to monitor him.

Having my baby taken somewhere else was so upsetting. I cried and cried but knew inside that it was for the best. I had to stay on the ward as I was recovering from the caesarean while my baby was on the floor above me. My husband and I spent all our time with him and never wanted to leave his side, he was so special to us. The staff on the neonatal unit where amazing: so caring and supportive. This helped us both.

'We were given a very special baby boy and whether he has a stoma or not he is still our son and having a stoma doesn't change a thing'.

Alfie was suspected of having Hirschsprung's disease, which is where special nerve cells called ganglion cells are absent in the intestine. It causes constipation and can create a blockage, which, if not treated, can cause serious problems like infection, bursting of the colon and even death. He had to have bowel washouts to empty his bowels, as he wasn't able to pass motions on his own. The doctors did a biopsy and the results were negative as Alfie was shown to have ganglion cells. My husband and I cried with relief when we were told that he hadn't got Hirschsprung's disease. After thirteen days in the neonatal unit Alfie was allowed to come home with us. We were over the moon, but that's when the problems started, I struggled to feed him because he never wanted his milk. I knew this wasn't right: he was being sick and his tummy seemed to get more and more distended. He used to scream like he was in pain.

I felt helpless towards him and made several visits to the hospital for him to be assessed. Finally when Alfie was five months old he had a second biopsy and it showed that he did have Hirschsprung's disease and would need to have pull-through surgery to remove the part of intestine with no ganglion cells. The day Alfie had surgery was a terrible time for us all. We were so worried and upset because we didn't know how much bowel he would lose or what the end result would be.

Alfie's surgery was over five hours long. It seemed like forever and all we wanted to do was see him. The surgery went well: he had Short Segment Hirschsprung's disease, which meant he only had a small amount of intestine removed. He made a good recovery and returned home.

However, after surgery Alfie still seemed to suffer, and a few months down the line we had to restart the bowel washouts again as he was much the same as before, not emptying his bowels and crying with pain. After several hospital visits we found that he had a narrowing of his intestine which needed to be dilated every few months to stop it closing up altogether.

We carried on with the bowel washouts until they stopped working properly. Then we started to use suppositories instead, but only if we really needed to as this caused a lot of added pain for Alfie. In the end I could no longer give my son anymore of these as I couldn't see my baby in all this pain.

Soon after Alfie became really poorly and ended up in hospital with sickness and diarrhoea; he couldn't even keep water down. He was getting so weak and his gut needed time to rest so he was put on TPN - all the nutrients his body needed where fed straight into the blood stream. He had to be put to sleep to have the TPN tube fitted and at this stage we discussed with the possibility of Alfie having a stoma. The surgeon thought this way he would have a better quality of life. Then Alfie became so poorly that the decision was taken out of our hands and we agreed for the ileostomy to be done at the same time as the TPN tube was put in. Alfie always seemed to be in pain when using his large intestine; an ileostomy meant he wouldn't be using it and it could rest.

Alfie has had his stoma for six months now and it was the best thing we have done for him ever. He now has a better quality of life and most of the time no pain. He attends a local crèche twice a week and enjoys playing with other children of his own age. This wasn't at all possible before the ileostomy. He is much happier now with his stoma and has put on a little weight and people say he looks a lot better.

As a mother of a child with a stoma it has been very hard to get used to. I found it hard to even look at it after his surgery but knew it was there and I had to get on with it, so that's what I did. I didn't want this for Alfie, my baby, but the decision was taken out of my hands, I had to do what was best for him. I started to empty and change the bags as often as I could to get used to it. Now both myself and my husband are experts at it.

I am finding out new things to help Alfie everyday and this includes the sash security and leakage belt; this belt has been amazing. The difference this had made to Alfie's life. He now has no leakage at all and I will never go anywhere without it.

I have made several friends through the Internet, parents with children with Hirschsprungs disease, and we share our experiences. Alfie is too young to know he is different from other children of his age but is so good when his bag has to be changed or emptied.

As his mother, I have had many ups and downs of emotions through this journey and know that it is not all over yet. I have to stay strong for the next time Alfie has to go into hospital to undergo more biopsies and dilation of his narrowing. Each time I get a little stronger and will carry on until we get Alfie sorted. What happens next for Alfie depends on the outcome of the biopsies - either way he has to have surgery again, whether it be a pull-through or removing the narrowing of his intestine.
We don't know what the future holds for Alfie, but as long as we stay strong, together as a family, we will get through this. I believe that everything happens for a reason: we were given a very special baby boy and whether he has a stoma or not he is still our son and having a stoma doesn't change a thing.

Mrs. Kerry Stafford

What is Hirschsprung's disease

- Hirschsprung's disease occurs in 1 out of every 5000 live births and is much more common in boys than girls.

- Ganglion cells are formed in the baby's intestine soon after development begins in the womb. These nerve cells are needed for intestinal muscles to move food and digested matter onward by a series of wave-like contractions called peristalsis.

- In Hirschsprung's disease these ganglion cells are formed in the upper bowel but do not spread to the lower bowel, thus normal peristaltic movement cannot occur, resulting in constipation and blockage.

- In infants, symptoms include failure to pass meconium within the first 24-48 hours, bile vomiting, a distended abdomen and poor feeding.

- Hirschsprung's disease is diagnosed by using a number of techniques. The most vital diagnostic tool is the biopsy whereby a tissue sample is taken from the large intestine and studied under a microscope to see if ganglion cells are present.

Sources of Information and Support

Hirschsprung's and Motility
Disorders Support Network
(HMDSN)
Web: www.hirschsprungs.info

Leaflet on Hirschsprung's disease
available from:
Core
Tel: 0207 486 0341
Email: info@corecharity.org.uk
Web: www.corecharity.org.uk

Families and children find time to connect at the August Breakaway Weekend 2010

Breakaway August Weekend 2010 was an amazing success! I always wonder how we can outdo the last one - but we do!

In August, we welcomed many new families to this event, which was a delight and a sign that our determination to reach out to families who feel so alone is succeeding!

Jack's Mum shares her Breakaway experience...

"When we arrived at the Youth Hostel I was so nervous. I actually contemplated cancelling the weekend!

Having never met any other families or children with bladder/bowel problems - I felt daunted at the prospect.

As soon as we arrived I felt like I was at home, there was no awkwardness. I felt really at ease. Thinking back those who came that Friday, were all smiles, it was just amazing - I felt an instant connection with everyone.

After the team games, we went back to our room, as we had an early start the next day. Jack said, "Mum, I have had the best time ever".

The hard work that the Trustees put into this event, so that we can have a ball is nothing short of a miracle. I can never repay them for what it has given us.

The friendships that we have made will stay with us for life, it is like a little piece of heaven our children can be "normal" because they are not alone.

Jack has always had moments of such deep despair, even as his mum I can't help him as I don't know what he's going through.

Since Breakaway, we have actually had a full week of happiness from Jack, with no dark days where he feels so very unhappy. I know it sounds drastic but he constantly tells me he wants to die, when he is in his dark place. This is the first time we have had a happy and content little boy!

He is counting the days to the December Breakaway, and we are keeping in touch with a few of the families we met, so the little piece of heaven you made for Jack will continue every time we get together.

We can't wait to see you all again real soon."

The above experience written by Jack's Mum says it all and is why Breakaway exists today - to continue to reach out to families, and to young people like Jack!

Julie Bastin
Chairperson
Breakaway Visits

Hannah chats about Breakaway's latest weekend event and more...

I was super excited about this Breakaway as my best friend from the hospital was coming with her Mum. Also my Urology Nurse Jeni was coming for the whole weekend! She is my favourite and has helped me and Leah, my friend so much. Jeni was a little worried that we were going to play tricks on her. It was not me that pushed her in the river it was the activity instructors, but it was VERY funny!

I went on the high ropes four times with my Daddy, I was too scared in May. My favourite activity is canoeing! We did lots of crafts on Sunday, making friendship bracelets, painting, sticking and making a terrible mess with glitter- it was really fun!

There were lots of new people at Breakaway this time, which was exciting. I made new friends and I can't wait to see them all at the Christmas party.

I am trying to persuade my Mum and Dad to let me do a sponsored bike ride from my house to Grandma and Grandad's house. It is nearly 30 miles. Daddy is looking to see if he can find a safe cycle route to follow then maybe I will get to do it. I want to do it so that other children like me can come to Breakaway and have a fun weekend and not have to bother about being a bit different.

Hannah Adams Aged 9

breakaway
putting smiles on young faces

Call us on: 07903220040 or email us on: break.away@tiscali.co.uk
or visit our website on: www.breakaway-visit.co.uk

If you would like to make a donation to Breakaway...
visit: www.justgiving.com/breakawayvisits

JustGiving

Join us for our 4th Breakaway Weekend

We're going back to the forest!

YHA National Forest East Midlands

29April 2011 for 3 nights

Put some smiles on young faces, chat and share your experiences in a relaxed friendly environment, but more importantly come and have fun!

The cost of three nights full board accommodation is just £165 per person. All rooms are 2-4 beds and en-suite. There is also a bar, bistro and coffee shop.

For further information on this and future events.

Call us on 07903220040

Email us on
break.away@tiscali.co.uk

Visit our website on
www.breakaway-visit.co.uk

breakaway
putting smiles on young fac

Aled - inspires his parents to form The VACTERL Association Support Group...

Aled pictured here was born with several problems which come under the umbrella name of VACTERL or VATER association.

The VACTERL Association Support Group was started in 2005 by the parents of Aled Griffiths who was born in Sept 2003 with the condition.

Aled was born at Derriford hospital in Plymouth in 2003 after a fairly quiet pregnancy. Although Gaile was being reviewed by the hospital every few weeks because of gestational diabetes we had no idea how our lives were about to change.

The first week of Aled's life was an absolute nightmare, first the joy of him arriving and then the realisation that things were wrong. Aled had a colostomy within 24 hours of birth (this remained with him for the first year). We were then told of new problems on a daily basis.

We searched everywhere for information about VACTERL Association but found that there was no one in the UK that totally covered the wide range of problems that we needed help with, and this left us feeling quite isolated.

After things started to settle down and we were into our many hospital visits around the UK, I (Neale) decided that I needed to find other people in similar circumstances which led to me create a website about Aled (www.alledgriffiths.co.uk). I was totally devoted to its creation, possibly my way of coping with the stress. Once that was completed I decided to create a chat room with one of the broadband providers, this was a small success but I then realised that I wanted more than just a chat room, I wanted to help in bigger ways.

Thanks to friends and families who donated money to get started, we created a website, which although basic was enough to start us off.
In December 2005 we went live with www.vacterl-association.org.uk

From then on, things took off...more people joined, we met some families and spoke to loads more on the telephone. Eventually we had meetings, these have shown to be a great success, greatly enjoyed by all that have attended, and each one has grown in size. We have members from the furthest parts of Scotland right the way down the country to Plymouth.

As a family, things have calmed down, we still have all the hospital appointments, bowel management routines for Aled (which have been a great success) etc, Gaile is back at work as a nurse and I am back at sea as a Chief Petty Officer in the Royal Navy. Aled is to have a bladder augmentation in November and at the same time they are doing the ACE and Mitrofanoff. This will be a worrying time, but as with the other eight operations, we will take it as it comes.

The future for the support group...
We want the support group to keep growing, have more meetings and have much more of an impact on how we can support the families while they are going through what may be one of the hardest times in their lives.

How to contact the group:

Telephone: 01752 482568
Email:
General information:
info@vacterl-association.org.uk
Help and support:
support@vacterl-association.org.uk
Web: www.vacterl-association.org.uk

VACTERL Association Support Group

What is VACTERL Association?
VACTERL association is characterised by the sporadic, non-random association of specific abnormalities. Each letter stands for a specific abnormality.

- **V: Vertebral anomalies**
- **A: Anal anomalies**
- **C: Cardiac anomalies**
- **T-E: Fistula +/- eosophageal atresia anomalies (American Spelling)**
- **R: Renal or Radius anomalies**
- **L: Limb anomalies**

A person with three or more problems in any combination may be recognised as fitting in to the VACTERL Association. However, VACTERL Association is not a diagnosis. There is no one cause for the association of these problems in individuals.

Aims of the support group are:-

- To develop a network that will provide advice and support to children and parents/carers of VACTERL children.
- Advise the medical profession of the Association.
- Develop a system of promoting self esteem for the VACTERL child.
- Generate opportunities for the VACTERL child.
- Provide opportunities for VACTERL children to meet each other and develop supporting friendships.

better together

Gutless Kayaking...an interview with Justin Hansen

Justin was diagnosed with Crohn's disease in 2003, here he talks openly about his patient journey - and tells us about why he is kayaking 240 miles from Manchester to London!

Q: Tell us a little about yourself.

A: I am 50. I'm currently studying Psychology (BSc) at the University of Portsmouth and am two years through the three year course. I had to defer for a year (2009-2010) because I had a stroke and needed open heart surgery. My hobbies include playing sports and travel. I have a brother and two sisters, all of whom are helping with this challenge, plus, of course, my Mum.

Q: How did your illness come to light?

A: From 2001-2003 I started to develop a series of seemingly unrelated ailments. Strange rashes appeared, and my joints seized up, my nail beds became infected. At one point I had over 100 mouth ulcers. My Doctor was not able to help. By March 2003 I was very ill and losing weight. My sister took me to the local A&E Department where I was admitted to hospital. After a few days of tests it became clear that my large intestine (colon) needed to be removed. Tissue was sent to the pathology laboratory, and diagnosed. I was advised that I had Crohn's disease.

Q: How did your illness affect your work, family, friends?

A: I have not been able to work full time since 2003 and rely on support from family and friends. Generally, this illness has brought me closer to family and friends.

Q: How have you been supported by healthcare professionals, family and friends?

A: I totally rely on St. Mark's Hospital for my continuing care. Family and friends help with adapting my feed for holidays, preparing documentation for airlines, airports and customs, constantly monitoring my health and the underlying condition, plus support some of my more off the wall ideas (like this kayaking trip).

Q: What kind of help/treatment do you require on an ongoing basis?

A: Other than a few pills every day, I need TPN (total parenteral nutrition) due to short bowel syndrome. This is a lifelong condition so I've learnt the procedures needed to manage the treatment. I learnt this over six weeks as an inpatient at St. Mark's in 2004.

I have a tube emerging from my chest to which I attach a 3 litre bag of liquid nutrition. It takes about 15 minutes to both connect and disconnect the feed and this requires a complex aseptic technique. It's not rocket science exactly, but it's really important to make sure that the whole process remains sterile as the feed flows directly into my bloodstream. I need to do this every day and it takes about 12 hours for the whole feeding process to complete. I also have a stoma (jejunostomy) which tends to have a mind of its own! It can be either no problem or a total nightmare. Generally, if something goes wrong it's more of an embarrassing inconvenience than a full blown crisis. But in any case it's essential to have some spare clothing and replacement supplies close at hand. Local stoma care nurses and St. Mark's Hospital keep me updated on new equipment and supplies.

Q: How do you cope with your illness/condition?

A: Sometimes, I don't cope. It's not easy. I have a room at home full of hospital equipment and supplies. Sometimes I feel like chucking the whole lot out of the window. It took a long time before I was able to talk openly about what has happened to me. I've been in therapy for the last few years to try to help me come to terms with my changed circumstances. I have found the mental struggle much harder than the physical.

The practical side of things is fairly straight forward once you know how. The TPN can be difficult to manage because the procedure calls for a sterile environment. Also, it's very restricting because of the sheer volume of supplies needed on a daily basis. The stoma can be a real nuisance when things go wrong at the wrong time, but I usually have enough supplies to deal with that and can sort myself out quite quickly.

The best thing for me has been to be as open and honest about everything as I can. This was very difficult at first, and is something that I worked very hard on. Early on, I created more difficulties for myself by trying to conceal my condition from others. I'm trying to learn to give others the opportunity to accept me as I now am.

Q: How did the idea for Gutless Kayaking come about?

A: I did a bit of fundraising in 2007 and thought, after last year's experience (stroke and open heart surgery) that I should have another go now whilst I still can. I had many ideas (mainly related to outdoors and fitness, eg. hiking Hadrian's Wall, kayaking the Thames, London Marathon etc.,) which I asked friends about, this one seemed the most popular.

Q: Where are the start and finishing points of your journey and how long will it take?

A: Start: Bridgewater canal, Eccles, Saturday 11th September

Finish: Grand Union canal (Paddington arm), Perivale, Friday 1st October

Q: Who is involved and why?

A: Very good friends of mine, who I've known for years and can totally rely on: Stephen Cassidy, old Aussie friend, I've been motorbiking with him in the USA, last seen at the bus station in Mombasa, Kenya! Mitchell, another old Aussie friend, travelled with him in Alaska, Uganda, Finland, India, USA, JP, I am his oldest son's godfather. We go camping every year. Steve Mason, a new friend, he has recent paddling experience in UK, and is helping with fundraising.

Q: How will you cope during the journey?

A: To avoid dehydration I will need to be connected to my liquid nutrition for 24 hours a day. This means I will need to wear my backpack, containing the feed and an electrical pump, at all times. We are restricting our daily target to 12 miles in order to ensure that I can cope physically. Because the feed has to be refrigerated up until use, BUPA Home Healthcare, will be making regular deliveries to us en route.

Q: What will the funds raised go to?

A: Monies raised will go directly to St. Mark's Foundation, which funds medical research and education. Two big projects they are currently working on include: Intestinal Tissue Engineering and Intestinal Growth Factors.

Q: Can readers' track your progress online?

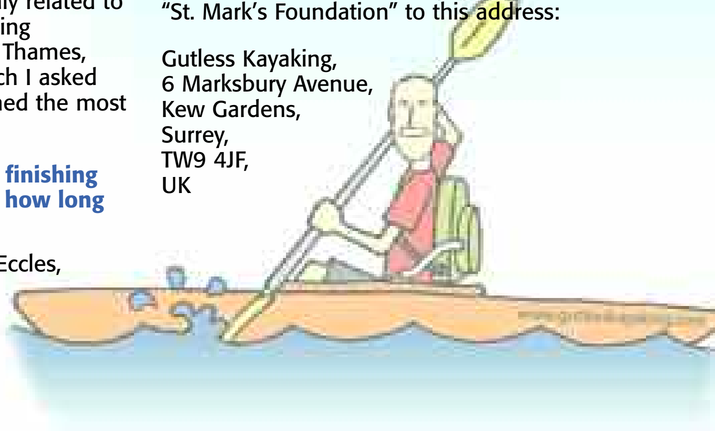
A: Yes, on the website.
www.gutlesskayaking.com
We will be publishing a blog as the trip progresses. And, on the map:
www.gutlesskayaking.com/blog/what/map

Q: How readers' can get involved?

A: The website has all the details about the trip, my condition and how to donate etc.,

To donate online:
www.justgiving.com/justinhansen
or by post: Please send cheques, with your contact details, made payable to "St. Mark's Foundation" to this address:

Gutless Kayaking,
6 Marksbury Avenue,
Kew Gardens,
Surrey,
TW9 4JF,
UK



Pathways to a colostomy

Primary Progressive Multiple Sclerosis (PPMS)

Marjorie Corner writes - “I remembered seeing a mention of a colostomy being used as a rare management tool for MS – there was a possible solution.”

Readers’ PANEL contributor

I have Primary Progressive Multiple Sclerosis (PPMS). PPMS doesn’t relapse and remit or have widely varying symptoms but begins, usually later in life (I was fifty-eight), with difficulty in walking and then progresses – I began by often turning my feet over and now fourteen years on I can’t walk at all, in fact none of the bottom half of my body functions properly inside or out. I think I am fortunate. I “live” in a wheelchair, manage, stubbornly, on my own with no carers etc. To date I have good use of my hands, arms, eyes and brain.

“So what” - I hear you think as you read this! Well ten years ago, because of problems with urinary incontinence, after much pleading, I was “allowed” an indwelling catheter - no more pads, no more getting up at night with associated risk of falls. Brilliant, that catheter changed my life overnight. Soon, though, I was having trouble with my bowel function. Not constipation nor, unless I ignored everything, faecal accidents but trouble getting anything down into my rectum at all. I had tried everything the doctors could suggest, no good. The unpleasant, and time consuming, option was deep manual stimulation the whole process taking half to three quarters of an hour two, often three, times a day. Visiting friends or meeting up for coffee was impossible. I gave up all the committees etc I was on because getting to anything on time was virtually impossible, indeed I was hardly going out at all except for popping down to the local shops for a few essentials.

On my way to my annual neurological appointment I was thinking over the notes I had made. What, I thought, if there was a catheter equivalent for my bowel? Then I remembered seeing a mention of a colostomy being used as a rare management tool for MS – there was a possible solution. I asked the MS nurse about it and, frankly, a look of absolute horror came over her face. Not much help likely there I felt.

However, there were other routes. My GP was supportive. He referred me back to the colorectal consultant. We had known one another a long time and when I made the colostomy suggestion, his face lit up – a solution for a problem he had already admitted, after thorough tests, he couldn’t solve. In a few months my life was again changed overnight, literally this time, as the operation was done at 2am! That was eighteen months ago.

I LOVE my colostomy. I am back in control of my life. I have been away with my daughter and her family and have now booked a holiday abroad. Magic.

Recently I met a former stoma nurse at an exhibition of “stoma kit”. He had met five or six other colostomates due to MS and ALL felt the same way as I do. It’s an unusual solution, to what is a common, but rarely mentioned, problem within MS – a complex disease in all its forms.

Marjorie Corner

What is... Multiple Sclerosis (MS)

Multiple Sclerosis (MS) is the most common disabling neurological disease among young adults and affects around 100,000 people in the UK. MS is most often diagnosed in people between the ages of 20 and 40, and women are almost twice as likely to develop it as men.

There are main three types of MS, each with its own characteristics, each unpredictable in its effects.

- Relapsing Remitting MS
- Secondary Progressive MS
- Primary Progressive MS

Multiple Sclerosis (MS) is the result of damage to myelin – a protective sheath surrounding nerve fibres of the central nervous system. When myelin is damaged, this interferes with messages between the brain and other parts of the body.

For some people MS is characterised by periods of relapse and remission, while for others it has a progressive pattern.

MS can cause a variety of symptoms e.g. dizziness, numbness, fatigue, blurred vision, speech or swallowing difficulties, bladder or bowel problems etc. Many people experience only a few of these symptoms and it is unlikely that anyone will develop them all.

For more information contact:
Multiple Sclerosis Society
Free MS Helpline
0808 800 8000
www.mssociety.org.uk

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Problematic stomas...
Stoma Granulomas

Written by
Toni Johnson RN Dip NS, ENB 980, ENB 998 & Level 3 Stoma Care Course
Stoma Care Nurse Specialist,
Homerton University Hospital

Granuloma is a medical term for a mass of immune cells that forms when the immune system attempts to contain foreign substances, such as suture fragments. A granuloma therefore is a type of inflammation that causes a small nodule to develop due to the macrophages (white blood cells). Macrophages specialise in the removal of bacteria and other micro-organisms or of cell debris after injury. Granulomas are seen in a wide variety of medical conditions.

What causes Stoma Granulomas?

Stoma Granulomas give the appearance of small nodules of hyper granulation tissue, which are usually 2mm in size, but they can be bigger up to 10mm in size. They are friable (crumbly) and can bleed easily. They occur mainly at the muco-cutaneous junction (at the edge of the stoma between the skin and stoma mucosa) or they can occur anywhere on the surface of the stoma.

There is no definitive cause for why stoma granulomas develop but the following may give some reason to them occurring.

- These small nodules of hyper granulation tissue often develop where sutures were inserted at surgery and they can appear many years after stoma formation surgery.
- Repeated trauma from the stoma flange or pouch can also be a reason. Bleeding from stoma granulomas during your pouch change maybe due to over enthusiastic cleaning so be gentle with regards to cleaning your stoma and the surrounding skin.
- Prolonged faecal irritation to an area of the stoma or an allergic reaction to the plastic in the pouch may also be a possible cause for stoma granulomas to develop.
- Wearing tight clothing, waistbands or belts on the stoma will cause a friction force on the stoma surface, which may assist granulomas to develop.

Patient Discomfort

As mentioned stoma granulomas can cause bleeding and discomfort. Some times the bleeding can cause the stoma pouch to dislodge or, if the granulomas are large they can prevent the proper placement of the pouch over the stoma. However, not all patients who have stoma granulomas experience symptoms of bleeding and discomfort. The appearance of stoma granulomas can obviously be visually disturbing. The important thing to remember is that they are not harmful. Ask your local stoma care nurse for a review to assess the area. They will inform and reassure you about the condition and provide you with a suitable treatment plan.

Treatment & Appliances

Stoma granulomas are treated if they become painful, uncomfortable or if bleeding impairs pouch adhesion and causes leakage problems.

The treatment for stoma granulomas can be variable but the main treatment option is the application of silver nitrate to the stoma granulomas approximately two to three times a week. This cauterisation treatment can cause a reduction in the size of the stoma granulomas, as well as causing discolouration of the stoma surface.

However, stoma granulomas can frequently reoccur. Surgical removal is an option but it is usually reserved for when numerous stoma granulomas are present either at the muco-cutaneous junction or the entire surface of the stoma. The application of a stoma paste (Dansac Soft paste or Convatec Stomahesive paste) to the muco-cutaneous junction can help prevent friction to this area. Checking and re-sizing the stoma pouch aperture to prevent friction trauma to the stoma surface is required. Placing a lubricating gel in the pouch (such as Hollister Adapt Lubricating Gel or OstoMart OstoZyme Gel) can help prevent the pouch rubbing on the stoma surface.

Regular checking of your stoma size to ensure the aperture of your pouch fits correctly is necessary, especially with any weight gain or loss. There is also some suggestion that for patients who have a parastomal hernia, the bulge caused by the parastomal hernia makes the stoma surface rub against the pouch resulting in friction force. Stomas that are short and distorted, resulting in leakage problems can also have a higher incidence of developing granulomas. Ensure clothing, such as waistbands or belts are not tight fitting over the stoma. Care must also be taken to ensure that cancerous growths or any other gastrointestinal disorder are excluded before treatment starts.

Conclusion

The causes and the treatment of stoma granulomas are not certain but your local stoma care nurse specialist, is the most experienced person to manage stoma granulomas.

Readers' writes

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

Dear Editor

I have just read the article 'Ten Weeks Later' which I think is a very positive and encouraging article for anyone with a new stoma.

Having had both a colostomy and a urostomy for twenty-two years I can be classed as someone who is often quoted to people about to undergo surgery. I don't hang-glide or pothole but I returned to full time teaching, play cricket when my husband's team is desperate for a fine leg, have ridden horses and travelled abroad.

However, like Susan Fifer, I did find it mildly irritating to be told that various celebrities had a stoma. My thoughts at the time were that I was not over concerned with how the wealthy and privileged coped but was far more eager to know how Mrs So and So coped with a full time job and children! But I say to Susan take heart and carry on, feelings and emotions can change over time. There will be good and bad days but the bad days do recede.

Ten weeks after my surgery the euphoria of still being alive, after the second bout of cancer, dimmed when faced with the enormous amount of equipment and major lifestyle changes that having two "alien" bits entailed. There were problems to begin with: frequent leaks from both stomas, umpteen readmissions to hospital, infections etc. but most of these were teething troubles. Problems iron out eventually and I have almost forgotten what life was like before my stomas.

Susan Fifer's article offers a lot of practical advice but more importantly I feel shows a very positive spirit for embracing a new lifestyle. Long may this continue and I look forward to her next article.

Yours Sincerely
L. H. (Mrs)

Dear Editor

I received the devastating news that I had cancer of the rectum in 2007, just a few weeks before my daughter's wedding. The surgeon and oncologist kindly agreed to leave the treatment and surgery until after the wedding. My daughter was married in a tepee in our garden and it was such a beautiful and happy day. Two days later I started radiotherapy, and had surgery a week after that. We all know the long and painful path it takes. Sometimes the despair we feel is mixed with the emotions of being grateful that it was diagnosed and that we are still in the land of the living.

The only visitor I agreed to have, other than my husband and children, was somebody a friend knew who had been through similar problems several years earlier, and what a boost that gave me. She arrived looking extremely glamorous when I looked like my own grandmother towards the end of her life! She didn't tell me that it was easy and she told me some very embarrassing stories and was able to laugh about them, but she did show me that there was light at the end of the tunnel and that in time I would feel like a human being again. She also gave me her latest copy of Tidings.

I could hardly bear to open it at the time. When I finally did I felt quite depressed at some of the stories, but as I began to get my strength back I read it avidly and learned many helpful tips which has prompted me to respond to Susan Fifer's article. This tip was given to me one year after surgery when I attended a volunteer day at The Colostomy Association and it has turned out to be invaluable. I was unwilling to empty my drainable pouch in other people's toilets because the contents were difficult to flush away therefore I didn't go far from home or I would arrive home with a very full pouch. The answer was so simple – line the toilet bowl with toilet paper – and whoosh – down it went. That, and discovering a bag that is not actually traditionally suited to my problem – I have a colostomy not an ileostomy and I do not have an inverted stoma but I wear a convex drainable bag because it suits my very allergic skin not to change the bag often, and the adhesive is so good I have only had one leak in two years. So some of the ways that we deal with our problems can be unconventional, but they work for us.

So, I agree it's a steep learning curve and when I look back at those dark, early days I would never have believed that I am now living a healthy and only a marginally restricted life. I know there might be further hurdles but I have certainly learned that we are all probably much stronger than we think we are. Good luck, Susan.

Best wishes
J.W. (Mrs)

A number of colostomates do find it easier to use a drainable bag. However, before using a convex appliance, ostomates are advised to contact their stoma care nurse as long term use of this type of flange may cause soreness or bruising.

Readers' writes

Dear Editor

The article, 'Problematic stomas. Dips and creases' in the current issue describes the difficulties in applying colostomy pouches when the skin around a colostomy is uneven, for example, has a pronounced hollow. It suggests a variety of measures that can be employed to overcome this. However, one very important technique has been omitted.

I am a retired consultant surgeon and three years ago had to have an abdomino-perineal resection that left me with a deep hollow to one side of the colostomy and also a large prolapse of the colon. At the age of eighty-eight, I did not wish to have a further operation and for two years struggled with all the devices you describe but could not find a way to apply a pouch that would not leak unpredictably or detach within 48 hours. The prolapse was difficult to control.

However, a year ago I was recommended to try the OakMed semi-permeable membrane Microskin because of its extreme flexibility and ability to adapt easily to uneven skin contours, such as hollows. After a short period of experimentation I found that the Microskin and drainable bag on its own (without any washers) could easily stay in place for seven days or more without any leakage. Moreover, I could control the prolapse well with a simple elastic belt device. This has transformed my life for the better.

I should like to recommend that OakMed semi-permeable membrane Microskin device should be given a full trial in any problem colostomy of this sort. It does require a period of familiarisation since it is different from the usual appliance. It is easily applied to awkward skin surfaces by smoothing it onto the skin without any stretching or deformity of skin or the membrane and no additional washer or paste is used. It is, of course, entirely suitable and comfortable for use in any uncomplicated colostomy.

Yours sincerely
D.T. (Mr)

Dear Editor

It is now thirty-four years since I had diverticulitis which resulted in my having a colostomy. The colostomy bags tended to leak. When the Bullen safe seals (flange retention strips) came I put them round the edge of the bags, but they still leaked from time to time.

My daughter who works as a nurse advised me to put the bags on my colostomy first and then put the safe seal on separately round the edge of the bags. Since then I have not had any leaks.

Yours sincerely
E.H.W.

Dear Editor

My wife has Alzheimer's and in May 2004 I took her to our GP to have her blood pressure checked. During the procedure the GP asked if I was alright. Oh yes! Caring for someone with Alzheimer's is unrelenting - 7 day a week, 24 hours a day. She wasn't satisfied with my reply and asked me to have a blood test before I left. Six weeks later I had an ileostomy due to cancer and after three weeks when my wife returned from respite care, I was back as the main carer. In October I had a reversal and all the plumbing put back in its proper place. Caring is so much easier when you are normal!

In 2005 I recognised symptoms similar to those I had in 2004 and sure enough the cancer was back. This time it was in the lower bowel for which I would require a colostomy. I had twenty-eight sessions of radiotherapy and seven of chemotherapy and on the 29th December the colostomy was formed. I knew that at some time my wife would have to go into a care home as the demands would be too much for me to cope with. My change in circumstances coincided with that moment and she moved into a care home without too much upset. I must admit I had the idea that I might take up the care role once I had recovered, but then I was told that there would be a further thirty weeks of chemotherapy following the operation. My wife's position changed from respite to permanent.

Once the chemo was completed I spent a week visiting friends in Northumberland and whilst visiting the Falkirk Wheel had a confrontation with a lady in a wheelchair as I came out of a disabled toilet, much like Vanessa described in the spring issue of Tidings. As soon as I explained about my bag she was full of remorse for her outburst.

From this point it was almost like the second new life the NHS had given me was just beginning. Being free from the 24hour a day routine with my wife I needed to rebuild my own life. I started playing bowls and after fifty years took up cycling. In 2008 I cycled the Macmillan way – Boston in Lincolnshire to Abbotsbury in Dorset – and raised about £1500 for Macmillan. Then in 2009 I did another sponsored ride to the Humber Bridge from Belton in Rutland, returning via the East Coast, this time raising almost £2000 for the Alzheimer's society. Like Bev Scott said people became much more important.

In November 2009 more chemotherapy was prescribed which turned out to be more aggressive than I had previously experienced. During the last chemo session I had an interesting conversation with another patient, who didn't have a bag. She was having big problems with diarrhoea. Never thought a bag would be a winner – just shows every cloud has a silver lining!

Yours sincerely
F.B.K. (Mr)

Readers' writes

Dear Editor

I first became aware of my Crohn's disease over twenty years ago and, having been equipped with 'external plumbing', learned of your excellent association.

My attitude to the colostomy was that it should be treated just like bi-focals: you either accept it or you reject it. Accept it and you get on with it: reject it and life will be much more difficult.

After a while my stoma prolapsed, which was as intriguing as it was problematical. I left an answer-phone message for my stoma nurse. At lunchtime she called me: "John – none of this 'Mr', rubbish – come straight in, I have got a bed for you". I was welcomed by hospital staff, who proceeded to remove a few more feet of 'pipe' and restored me to my former external appearance.

Oh my friends be warned by me - You can over-do the pain relief button. I did and hallucinated a bit afterwards. However, the recovery ward nurses were magnificent and helped me through.

Your journal is great and my copies have been helpful to friends who have been anxious about procedures.

Sincerely
J.D. (Mr)

Dear Tidings

I was interested in the article on laparoscopic bowel surgery in the Summer issue. I had a urostomy operation forty-four years ago. I remember not being able to eat or drink and staying in hospital for a long time. Also the pain and sickness was terrible. I was stitched from above the waist right down and still have the scar.

In May this year I had a colostomy done by keyhole surgery. When I came round from the operation I was surprised to be given water to drink. I did not feel sick and wasn't in pain. This article explains it all. I had breakfast the next morning and home in four days. I live alone but had friends to come and help me.

Also I'd like to reply to the first question on the dear nurse page. I also have this horrible smelling mucus coming from the rectum and need to wear pads. I was told before the operation this would happen and I could have the rectum removed to stop it. On my six weeks check-up I was asked about it but decided not to have another operation. I would put up with it. If I was younger I may have accepted another operation. I hope this helps the person who wrote the question.

Yours sincerely
M. F. (Ms)

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

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

If you want to be involved in the next issue of Tidings magazine **- simply drop us a line** via email:
associate-editor@colostomyassociation.org.uk
or write to:
Associate Editor
Colostomy Association
2 London Court,
East Street,
Reading RG1 4QL

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

Readers' PANEL contributor

Yours
Rosemary Brierley
Associate Editor

Tidings magazine is available in **PDF format. Simply visit: www.colostomyassociation.org.uk and register to download** or **email the editor direct at: editor@colostomyassociation.org.uk to organise a PDF to be sent to you.**

Enjoying life again...

Mike and his wife, Daphne, at their apartment in Madeira

Looking at Mike Lucas today you would never guess what he has been through since his surgery for diverticulitis in 2007 when it was discovered he had a perforated bowel. Mike tells us how the colostomy, which at first he thought would be temporary, became permanent and about the lessons he's learnt over the past three years.

Throughout most of my life I have been fit. I worked part time on a farm for years and played several sports, including tennis for teams in the Derby and Nottingham leagues. When I left school at fifteen I went to work as an apprentice for Rolls-Royce in Derby. At age seventeen I set myself a target to be the Human Resources Manager for the Rolls-Royce Main Works. It took me a few years but I achieved it. I clocked up forty-three years with the company, working mainly in HR. I found it to be very fulfilling but it was quite a pressurised environment.

In my mid twenties I developed stomach problems and was never without my packet of Rennies, even when I went to see Derby County play! My doctor treated me for Irritable Bowel Syndrome for many years. By the age of sixty-four my health became a problem in that I had serious stomach pain and frequent diarrhoea.

I had a colonoscopy which confirmed I had diverticulitis with abscess. I was not well and in August 2007 I underwent a Hartmann's procedure to form a colostomy. During the operation my surgeon found my bowel was perforated and he told me afterwards that this was at a life threatening stage. No wonder I felt gross before the surgery.

The hospital stoma care nurse met me a week before the operation, put an 'X' to mark the spot on my stomach and explained what a stoma was. I did not take much of it in, as I was more concerned about the surgery. After the operation my surgeon did say that he had found it a challenge. There is no doubt I underestimated how I would feel after the operation and indeed how long it would take me to get my strength back.

At home after the operation my scar healed completely after five weeks. Then suddenly a bullet size hole appeared on the scar line and it was weeping. A fistula developed and the brilliant team of district nurses dressed it for a month before I took over dressing the wound for the following two years.

Over the two years I gradually deteriorated due to adhesions from the operation. I experienced severe pain and vomiting that was originally occurring every six weeks or so and, over time, moved to every week. Each time I had an episode it would put me in bed for three days. Keeping a diary became pointless, as I could never predict how I would be on any given day. An attendant problem during this time was loss of appetite and weight. My wife, Daphne, is a terrific nurse and seeing me ill and not eating tested her patience to the full. My surgeon could not consider a second operation because I was underweight and not strong enough. At the consultations he did say, although I might be looking forward to a reversal, in my case it could turn out not to be possible.

To regain weight I worked with a hospital dietitian and on my visits to her longed to be overweight like some of the other patients who also waited outside her consulting room. Changing my diet to include blue top milk and a full English fry up every morning did the trick. In August 2009 after three false starts I entered hospital to undergo an attempted reversal and attempted tidy up of the weeping abscess and the adhesions.

Following surgery, which used the same scar line, my surgeon explained that it had not been possible to do the reversal. I was very disappointed but was sure that he had done the best he could. My weight dropped back to eight and a half stone (I am six foot two inches in height!) and it took me six months to get up to nearly fourteen stone. I bought trousers from thirty-two inch waist in two-inch steps over time to thirty-eight inch waist, which was quite an expense. It was worth it for people began to say how well I looked compared to the last time they had seen me. This caused me to thrive and really enjoy being free from pain and sickness.

The wound healed but then three months later, a fistula formed and continues to weep to this day. I continue to manage my bag and dress the wound, which at times gets me down. I worry about cross infection. My surgeon has suggested using silver nitrate caustic sticks to shrink the fistula, which I am trying. I would like to hear from anyone who can help me on this. Part of me says I wish it would stop weeping and another part of me says it is good that it is coming out.

Caring for my stoma…

When I first had my stoma in 2007, it did surprise me that in my hospital ward a few colostomates had decided that their partners were going to manage their bag changes. That wasn't going to be me! I saw my stoma care nurse but at the time was not well enough to take in all of her advice. I started with a two-piece drainable but moved to what I felt at the time was a simpler one-piece closed when I got home. I struggled over the next two years with my bag and experienced frequent serious leaks…once when I was about to present the awards at an annual dinner!

In hospital in 2009 a different stoma care nurse suggested I tried another type of one-piece closed bag. This did prove to be more reliable for me but not perfect. In April 2010 I went to my first open day organised by a stoma appliance manufacturer and supplier held in Lincoln and agreed to try their two-piece closed bag. I have got on well with the change and have had only rare, minor problems. This has boosted my confidence so much so that I have joined my local stoma support group and have also agreed to become President of my Rotary Club and Tennis Club.

Daphne and I have an apartment in Funchal Madeira and this year was my best year health wise since we bought it six years ago. Our next holiday is a cruise around the Caribbean. We have bought our large cases, which are actually much lighter than the medium size cases we are replacing and give me more space for my bits and pieces.

So what are the lessons I have learnt over the last three years?

- Colostomates are not all the same. We all have to find what is best for each of us.

- Talking and listening to others, at support group meetings or open days, helps. So does reading Tidings.

- Don't wait for a stoma care nurse to contact you. Contact the nurse yourself for them to check your progress and offer advice.

- Realise that you worry far more than those around you when you have an incident. They do understand and accept your situation.

- My stoma saved my life, I owe it respect.

- Set personal targets for the future and pat yourself on the back when you achieve them.

- Remember there are others less fortunate than you. I, for example, am not returning from a war zone with several limbs missing.

- Always be thankful that your partner, your family and your friends do work hard to make you feel that the future is bright.

Mike Lucas

Editors Comment

If you would like to share your story with Tidings readers

write to:

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

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

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Prevents *skin damage caused by adhesives*
Reduces *perspiration from treated skin*

Drug Tariff Listed

Product Code: RMCI
Description: OstoGuard Barrier Cream
Quantity: 60gram tube

Product Code: RMC2
Description: OstoGuard Barrier Cream
Quantity: Box of 20 x 2gram Sachet

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Drug Tariff Listed
Description: OstoZyme - Odour Neutralising Pouch Lubricant
Product Code: TCB3 Quantity: Box 30x8ml Sachets
Product Code: TCB6 Quantity: Bottle of 300ml

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Dear Nurse

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

Q: *After reading the last issue of Tidings may I query the answer given concerning constituents of medication appearing in the faeces. Many slow release tablets contain as part of their constitution non-absorbable cellulose components which appear in the faeces. I am on Felodipine as an antihypertensive agent and not uncommonly see what appears to be an unchanged tablet in my pouch contents. I am no expert at this but my local friendly pharmacist confirmed my suspicions.*

A: Tablets may appear in the faeces in the stoma pouch and may be unabsorbed which is why we suggest a review by the GP to investigate the possibility of having the medication in a different format. Our advice would always be to ask either your GP or your Pharmacist to check if this is the remnants of the tablet/capsule or whether the formulation needs to be changed. This should be done on an individual tablet basis to ensure correct medication and dose is absorbed.

Q: *I have had my colostomy for 12 years and irrigate every day. Recently I had a colonoscopy which revealed diverticulitis. When I mentioned this to someone they told me I shouldn't be irrigating with this disease as the colon wall is so frail it could burst with the water going through. Is this correct? I would hate to have to stop irrigating.*
Many thanks for your help.

A: If this is concerning you I would suggest a review with your Stoma Care Nurse and your Consultant. They will be able to inform you regarding the risks of irrigating with Diverticular Disease and the extent of the disease, which will have an impact on whether you can irrigate or not. There are some instances where we may suggest stopping irrigation but this is made on an individual patient basis and needs to be discussed with alternatives offered.

Your medical questions and queries about stoma care management are always welcome and important to us. Queries received by the Editor or CA are passed to Julie Rust RGN. Dip, N. MSc. CNS Stoma Care to review and answer. Answers are published in the next issue of Tidings. We are also interested to learn how you resolve your stoma care problems and how Julie's advice has helped you!

Q: *I was wondering if you have any ideas why I keep getting terrible spasms, it happens when lifting my leg or moving in my seat - it feels as if my stoma is going to burst and makes me scream. My tummy is so sore.*

A: You do not say how recently your surgery was done. This may be due to the recovery process in the early post-operative stage. However, if your surgery was a while ago this could be due to a parastomal hernia forming or adhesions. I would suggest a review by your Stoma Care Nurse who can examine you and decide on the best course of action. This may include an abdominal support or a referral to your consultant for further investigations into the cause of the pain and discomfort.

Q: *My father, who is 84 years old, had a colostomy bag fitted earlier this year after becoming seriously ill. Although he is better now, he has frequent problems with his bag bursting and I was wondering if there was any advice you can give us on how to try and avoid this happening. The bag is causing him great distress. Many thanks for your help.*

A: This is a difficult question to answer without a review to examine the stoma as it can be due to many different things. I would suggest seeing your Stoma Care Nurse who can remove the pouch and examine the stoma to identify the cause and offer suitable solutions. I am sure you will find them very supportive and hopefully this problem will be resolved and your father will feel more confident in his appliance.

Q: *Mine is a simple question that nobody seems to be able to answer. Why, since my colostomy operation (Hartman"s, due to acute diverticulitis) in September 2003, am I unable to eat (more than, say, a teaspoon of...) sauces, gravies, fried foods, mayo, oils, without getting acute diarrhoea, often occurring within an hour of consumption?*

These foods never adversely affected me prior to my op, and I am led to believe that Hartman's is undertaken almost at the end of the bowel/digestive process, so I am at a loss as to why this occurs. Can you answer this?

PS: Am I losing out on nutrients because of this? Also, I don't seem to be losing weight because of it!

A: All the examples you give contain fat/oil and this may not be digested properly and may be the cause of the problem. They should not be causing any problem with nourishment as the main absorption occurs in the small bowel. This may just be an inconvenience to yourself and may involve a little adaptation as to how much and how often you eat these foods. I have asked a few colleagues and they are all in agreement that this may be the cause of the problem although a question was what colour is the stool on these occasions as it may be due to a gall bladder problem if the stool is clay coloured and if so may need investigation from your GP.

Q: *I am a new (less than two months) colostomy owner. Yesterday was the first time I have driven my van since the operation. And I would like to know how others deal with the seat belt and their bags filling with gases and waste. If you can help me with this, I would truly appreciate it.*

A: Many people find driving is not a problem with the seat belt, however there are a few people who feel that the seat belt is causing a problem with the pouch. I have been informed by several patients that there is a device available from most car accessory shops which allows the seat belt to continue to work but maintains a degree of slack in the belt therefore preventing a problem with the belt.

Q: *It's now 11 months since I had surgery to remove part of the bowel also two hernias and adhesions and I've had severe abdominal pain ever since having the Ileostomy. I have to drain my pouch as much as 8-10 times within 24 hours. Also bothered with leakages.*

I use the washers also the adhesive strips but it still manages to come through. Also bothered with wind as the pouch blows up like a balloon.

In the last month I had a C.T. angiogram and endoscopy as surgeon thinks the cause is my blood supply.

I've lost over a stone and don't have any energy and very poor appetite. I am attending the hospital and on lots of medication which I faithfully take. The only thing to get pain relief is in taking Oramorph which I don't like being on, such a strong drug but no option. I'm only existing, and feel I have no life - the pains and discomfort of leakage is ruling my life.

Hopefully, you can give me any information that would help me get my life back on track.

A: You sound like you are really suffering at the moment but your Consultant seems to be trying to identify the cause and will then discuss a treatment plan with you. With regard to the excess wind problem this may be due to your diet and a diary of what you eat and the times of the excess wind in relation to this may be helpful to identify the cause. Also some patients find using peppermint (tea, mints or cordial), fennel (as a vegetable, tea, and tablets) or charcoal (tablets or biscuits) useful to reduce the amount of wind. I would also suggest a review by your Stoma Care Nurse to see if she can help to solve the problems with the pouch leakages. I hope this is helpful and you manage to get some relief from the problems.

Q: *I had my reversal 16 months ago and have done really well, I am able to eat almost anything. There have been two accidents no idea what caused them but it makes you very wary. My big problem extremely bad wind - social situations.*

Listening to my Doctor I have now cut out all green veg, onions, garlic, weetabix etc., I have porridge for breakfast and I eat root vegetables with my dinner which is not a problem but my dinner plate looks boring. Can you help me with my diet, I lead a healthy social life, dancing, swimming and holidays etc., I find the wind very embarrassing.

A: Many patients both with and without stomas find several things helpful to reduce the amount of wind they have. You sound like you have altered your diet to the point of it now being bland. It may be worth trying the following to see if these help. Peppermint, (tea, mints or cordial), fennel, (as a vegetable, tea, and tablets) or charcoal, (tablets or biscuits) useful to reduce the amount of wind. I hope this helps.

Q: *My Grandfather had a colostomy one month ago and the hospital have sent him an appointment for a colonoscopy next week.*

I understand the colonoscopy procedure, but I was wondering if it is different for a patient with a stoma. Please could you advise me how this procedure will be performed. I am concerned about the strong laxative medication given before the procedure as I feel the effects of this may distress him.

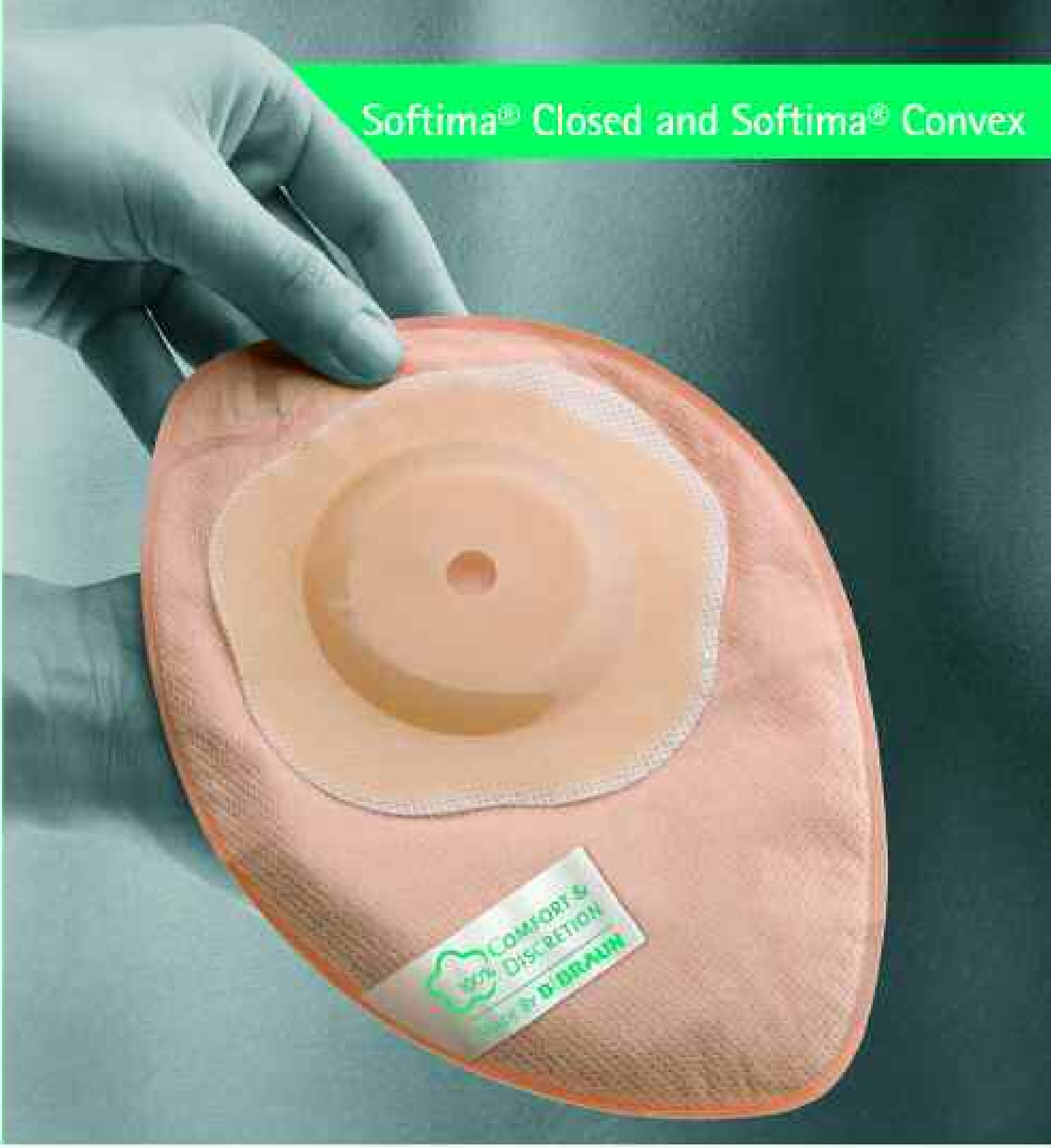
A: Patients with colostomies can have colonoscopies through the stoma without any major problems. It just needs to be highlighted to the department where he is having the test done that this is through a stoma (it should hopefully have been written on the x-ray card). Also it would be worth ensuring that he uses a drainable pouch as the need to take a bowel preparation medicine will cause his motion to be very loose and the pouch will need emptying more frequently.

Editors Comment

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

If so write in and tell us:
Colostomy Association
2 London Court, East Street
Reading RG1 4QL

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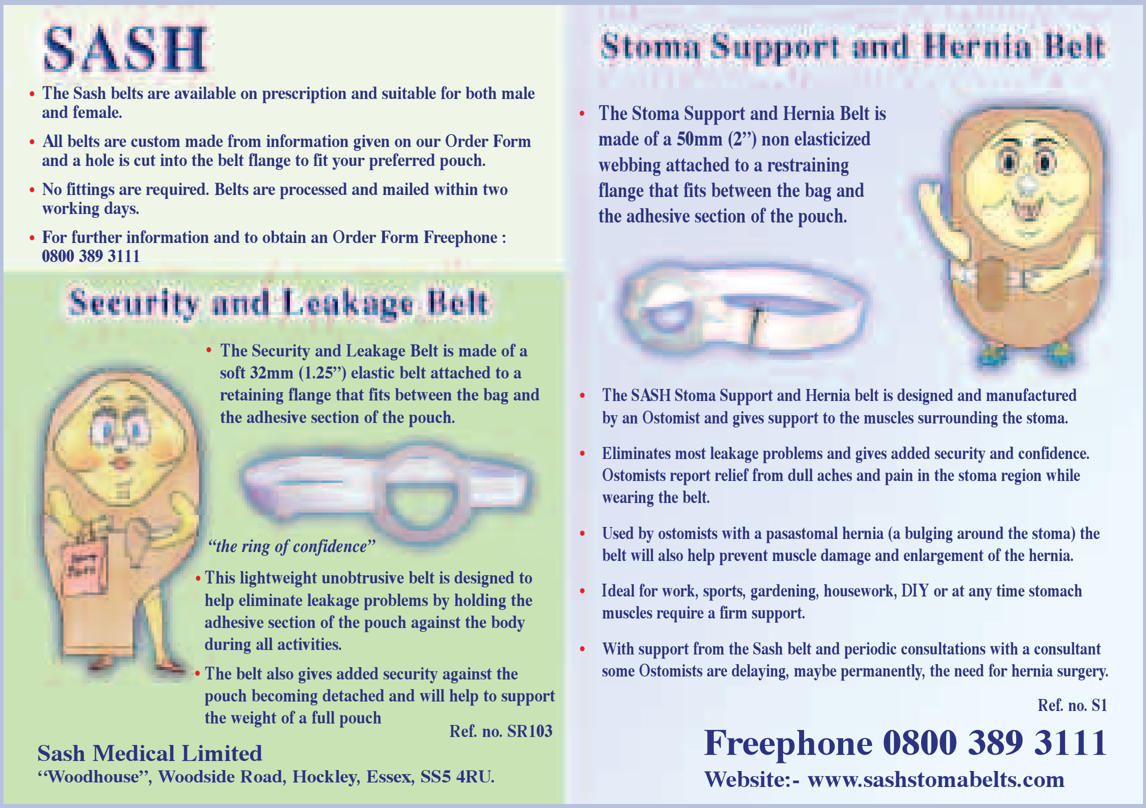

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- Eliminates most leakage problems and gives added security and confidence. Ostomists report relief from dull aches and pain in the stoma region while wearing the belt.
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For more information:
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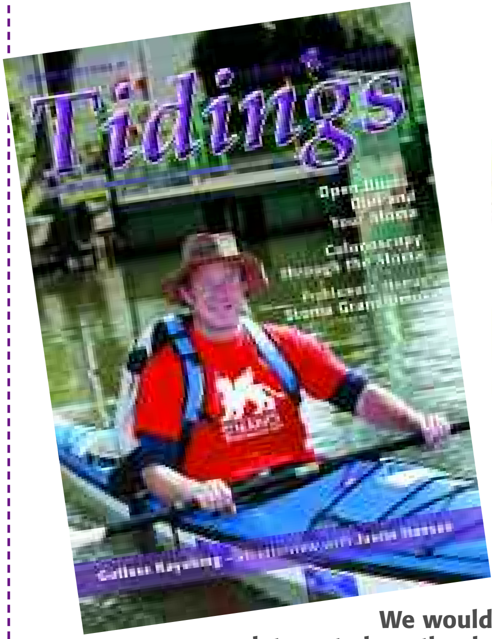
Telephone: 0044 (0) 1702 206502 Fax: 0044 (0) 1702 206502 Freephone: 0800 389 3111
E-mail address: info@sashstomabelts.com Website: www.sashstomabelts.com



Readers' Feedback Questionnaire

Tidings

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

We would like to think that we are producing an interesting, balanced magazine that readers look forward to receiving. To enable us to make sure that we are meeting your needs, and to gather ideas on how we can improve Tidings further, we have produced this questionnaire for you to complete and return to us.

We would like to thank you in advance for your help with our questionnaire. Please complete, cut along the dotted line provided and return to:- Tidings Editor, Colostomy Association, 2 London Court, East Street, Reading RG1 4QL, before 31st October, so that we can review the information and report on our findings in the January issue of the magazine.

About you... Voluntary information - we would be delighted if you would fill in your personal details using BLOCK capitals and tick the appropriate boxes. (If you wish to remain anonymous - we fully understand). Information gathered by this Questionnaire will not be passed on to any third party - thank you for your kind assistance.

Title: **First Name:** **Second Name:**

Address:

Postcode:

Tel: **Email:**

Male: ○ **Female:** ○

Age Group: Under 10's ○ 11-14 ○ 15-25 ○ 26-35 ○ 36-45 ○ 46-55 ○ Over 55's ○

Do you have a Colostomy ○ Ileostomy ○ Urostomy ○ None of these ○

About Tidings...

Overall, how do you rate the Tidings magazine?

Very Good ○ Good ○ Average ○ Not Very Good ○

How frequently do you refer to your Tidings magazine?

Once per Quarter ○ Once per Month ○ Once per Week ○ Daily ○

Do you keep each Tidings magazine? Yes ○ No ○

Do you pass Tidings magazine on to others to read?

Partner ○ Family ○ Friends ○ Carer ○ Other Ostomates ○ GP Surgery

Hospital ○ Support Group/s ○ Other please state: ____________

Readers' Feedback Questionnaire 2010

Continued overleaf...

Tidings Readers' Feedback Questionnaire 2010

Which of the following articles/features in Tidings do you read?

	Always	Sometimes	Never
Welcome	○	○	○
CA News	○	○	○
Open Door Features	○	○	○
Showcase - New Products and Services	○	○	○
Irrigation and You	○	○	○
Pathways to a Colostomy	○	○	○
A Colostomate Comments	○	○	○
Dear Nurse	○	○	○
Travel Features	○	○	○
Readers' Stories	○	○	○
Ostomy Community Features	○	○	○
Young Ostomates	○	○	○
Stoma Related Health Features	○	○	○
In Conversation with Support Groups	○	○	○
Aspects of Medical Care contributed by Medical Professionals	○	○	○
General Interest	○	○	○

Which of the following articles/features in Tidings do you find the most interesting?

	Very Interesting	Worth Reading	Not Very Interesting
Welcome	○	○	○
CA News	○	○	○
Open Door Features	○	○	○
Showcase - New Products and Services	○	○	○
Irrigation and You	○	○	○
Pathways to a Colostomy	○	○	○
A Colostomate Comments	○	○	○
Dear Nurse	○	○	○
Travel Features	○	○	○
Readers' Stories	○	○	○
Ostomy Community Features	○	○	○
Young Ostomates	○	○	○
Stoma Related Health Features	○	○	○
In Conversation with Support Groups	○	○	○
Aspects of Medical Care contributed by Medical Professionals	○	○	○
General Interest	○	○	○

Do you share your Tidings magazine with others, if so how many?

1 - 2 ○ 3 - 5 ○ 5 - 10 ○ 10+ ○

What other features/articles would you like to see in Tidings in the future?

(Please provide details.)

Are there any other comments that you wish to make about Tidings magazine?

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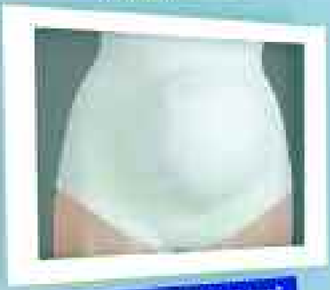
Mens Bespoke "darted cup" support device
*Patent Pending



Ladies Bespoke "darted cup" girdle
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Stoma Care Open Days...

Open days give ostomates the opportunity to meet and share experiences with other ostomates. Many people attend with friends and family and they can be very sociable events. Open Day events are posted on the Colostomy Association website throughout the year - visit: www.colostomyassociation.org.uk/get-involved/open-days

List of forthcoming Open Days:-

Date: 4th October 2010
Venue: Sports Hall, Spinal Injuries Unit
Time: 10am-3pm
Organiser: Northern General Sheffield SCD, Northern General Hospital Sheffield

Date: 5th October 2010
Venue: Bourne Hall, Spring Street, Ewell, Surrey KT17 1UF
Time: 1.30pm-6pm
Organiser: Stoma & Colorectal Dept. Epsom & St. Helier University Hospital - Contact Vicky, Vanessa 02082962640 or Jan 01372735925

Date: 13th October 2010
Venue: Devonshire House Hotel, Liverpool
Time: 1pm-4pm
Organiser: Royal Liverpool Stoma Care Dept

Date: Sat 16th October 2010
Venue: Heritage Motor Museum, Gaydon Warwickshire
Time: 10am-3pm
Organiser: Colostomy Association

Date: 20th October 2010
Venue: Coronation Hall, Ulverston, Cumbria
Time: 11am-3pm
Organiser: Morecambe Bay Hospital Stoma Care Dept

Date: 21st October 2010
Venue: Carling Suite, Westland Conference & Leisure Complex, Westbourne Close, Yeovil
Time: 11am-2pm
Organiser: Yeovil District Hospital

Date: 22nd October 2010
Venue: Best Western The Sea Hotel Sea Road, South Shields
Time: 10am-3pm
Organiser: Salts Healthcare

Date: 26th October 2010
Venue: Bannatynes Spa Hotal, Battle Road, Hastings TN38 8EA
Time: 1pm-4pm
Organiser: East Sussex Hospital Trust

Date: 29th October 2010
Venue: Apex Hotel, Dundee
Time: 11am-3pm
Organiser: Salts Healthcare

Date: Sat 30th October 2010
Venue: Wanstead & Snaresbrook Cricket Club, Overton Drive, Wanstead
Time: 12.30-3.30pm
Organiser: Stoma Care Dept. Whipps Cross University Hospital

Date: 5th November 2010
Venue: Aintree Racecourse - Princess Royal Suite
Time: 10am-3pm
Organiser: University Hospital Aintree


pelican
HOME
DELIVERY

"no one except another person in the same situation or with a similar experience can really truly understand what 'living with a colostomy' brings and means to one's life"...

Christine Davey writes about why she decided to set up a support group...

Lanhydrock Ostomists Group or LOG for short!

From left to right: Helen Robbins, Christine Davey and Mandy Rowe

My name is Christine Davey and in January 2006 after two operations I was left with a colostomy.

As I was not recovering as I should have I was re-admitted with further problems with the rectal stump and finally ended up with a huge DVT (Deep Vein Thrombosis) and spent a further five weeks in hospital eventually coming home at the end of May.

Although the stoma nurses were extremely good and helped me a huge amount, when you eventually leave the hospital you are mostly left alone to cope with your stoma. The only other person I knew that had a stoma was Mandy, who I met through Girlguiding which I am very involved with here in Cornwall. Mandy came to visit me in hospital and was a great help to me.

After these life-threatening events I decided at age 62 to retire from work and start an 'Ostomist' and 'Carers' support group.

In November 2009 with the help of my friend and carer Helen and co-opted friend Mandy we started the group!

The stoma care specialist nurses at the hospital sent out invitations to everyone in North, East and Central Cornwall and on the first meeting we had over 40 attendees.

We have now settled to around 20+ who attend each month and we meet on the third Wednesday in each month at Lanhydrock Memorial Hall, Lanhydrock, Trebyan, Bodmin, PL30 5AE between 2pm – 4pm. The groups name is 'Lanhydrock Ostomists Group' or LOG for short!

If you would like to join the group:
Contact Christine Davey on 01208 831471 or e-mail: chris.davey28@googlemail.com

Focus on other Support groups in South West England

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

Cornwall:
Lanhydrock Ostomists Group
Contact: Christine Davey 01208 831471
Optimists
Contact:
Sue Hatton 01326 340058

Devon:
Devon IA
Contact: Margaret Bond 01392 447374
CAT - Torbay
Contact: Donna Ashbrook 01626 854862

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

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

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

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 summer edition of Tidings.

Scotland

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

Glasgow:
Fittleworth Glasgow Stoma Support Group
Contact: Christine Daalman 0141 633 0592 or Charlie Sutherland 01698 822075

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

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

England - North

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

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

County Durham:
South West Durham Ostomy Group Bishop Auckland
Contact: Betty 01388 814535 Colin 01388 773757 Jen 01325 31266 Maureen 01388 818267

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

Lancashire:
Oldham Stoma Support
Contact: June Wilde 0161 6787086
Trafford Bowel Care
Contact: Jackie Carey (Secretary) 0161 7489659 Doreen 0161 9627818 John 0161 7484655

Merseyside:
I.C.U.P.S
Contact: Stoma Care Nurse 0151 6047399
Liverpool Support Group Crosby
Contact: Barbara Percy 0151 5292842 (Afternoon)
Olivia Thomas Suite University Hospital Aintree
Contact: Carmel/Pauline 0151 5292842 (Evening)

Northumberland:
Northumberland Cancer Support
Contact: Pat Fogg 0191 4102679

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

Tyneside:
Gateshead Health NHS Trust (Stoma drop in clinic)
Contact: Sister Heather Wilson 0191 4878989 Ext 2221
NHS Molineaux Centre
Contact: Lesley Brown 0191 2195656
Royal Victoria Infirmary Support Group
Contact: Gordon Weatherburn 0191 2341109

Yorkshire:
Airedale Stoma Support
Contact: Jenny Shaw 01535 652516 or Sue Hall 01535 210483
Bowel Cancer Support Group
Contact: Lisa Hall 01422 357171
CROPS (Colo-rectal ostomy & internal pouch support)
Contact: Gloria 0114 2879503
Dewsbury & District Ostomy
Contact: Janet/Eileen 0844 8118110
Rotherham Ostomates Caring Support
Contact: Contact CA for details
Scarborough Stoma Support Group
Contact: Sister Jean Campbell 01723 342388 Amanda Rowe 01723 342446
The Hull and East Riding Colostomy Support Group
Contact: Pete Smith 07989 565335 and Claire Price 07805 978151

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

England - Central

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

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

Nottinghamshire:
Nottingham Colostomy, Ileostomy & Urostomy Support Group
Contact: Rosemary Brierley 0115 982 7868

Nottingham Stoma Support
Contact: Mrs B Heath 0115 966 3996
North Notts Stoma Support Group (Sutton-in-Ashfield)
Contact: Tore and Nicky Norman 01773 715460

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

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

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

England - East

Bedfordhire:
Saturday Social Club
Contact: Karen Richards 01234 792278

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

Essex:
M.E.S.S (Mid Essex Stoma Support)
Contact: Paul Foulger 01245 224374
Jeanette Johnson 01376 511862
N.E.S.S (North Essex Stoma Support)
Contact: Mr K Harvey (Chairman) 01206 271425
Brian Waller (Secretary) 01206 540449
Optimistic Ostomates
Contact: Janet 01702 385510 Angela 01702 385509
South Essex Young Ostomy Group
Contact: Paul Gray 01708 501268
STEPS
Contact: Jackie Coleman 01268 451937
Redbridge Ostomists Club
Contact: Stoma Nurses: Chris/Lisa 0208 9708321

Hertfordshire:
Colonise
Contact: Gill 01727 851556
Stoma Fellowship
Contact: Andrea/Mandy 01438 781133

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

Norfolk:
Ostomy Friendship Support Group
Contact: Contact CA
Stars
Contact: Anne Brown 01603 661751

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

England - South East

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

Hampshire:
Southampton Support Group
Contact: Carole Summer 02380 446779
Wessex Urology Support Group
Contact: David Morris 02392 361048

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

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

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

Oxfordshire:
Oxfordshire Ostomy Fellowship
Contact: Pat Longworth 01235 524163

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

Sussex:
(SAS) Brighton & District Stoma Care support
Contact: Sylvia Bottomley 01273 554407
The Ostomy Friends Group
Contact: Jane Quigley 01323 417400 Ext 4552
West Sussex Princess Royal Stoma Support
Contact: Tina Walker 01444 441881 Ext 8313

England - South West

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

Cornwall:
Lanhydrock Ostomists Group
Contact: Christine Davey 01208 831471
Optimists
Contact: Sue Hatton 01326 340058

Devon:
Devon IA
Contact: Margaret Bond 01392 447374
CAT - Torbay
Contact: Donna Ashbrook 01626 854862

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

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

Wales

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

Northern Ireland

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

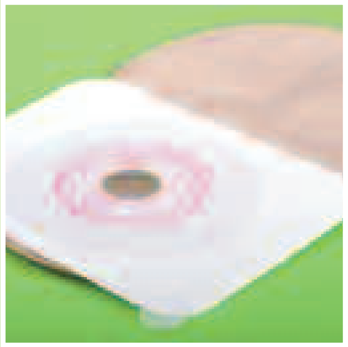
Eire

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

Editors Comment

If you know of a **support group** not mentioned in our listings please get in touch

e-mail:
editor@colostomyassociation.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 **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 £

② **Single donation:** (a donation of £15 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

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:** / / 2010

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:** / / 2010 **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'.

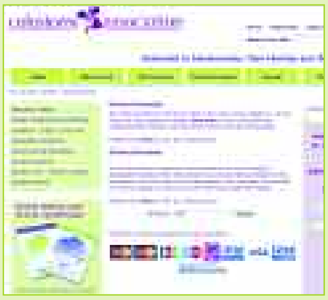
Here's how your donation helps us make a **difference...** to **fellow colostomates**

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

- **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.
- **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 £15.00 (or more) ensures we are able to continue to produce four issues of Tidings per year.
- **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.



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.**

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
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