

Spring 2011 | Issue 21

Tidings

colostomy association

Dedicated to Colostomates their Families and their Carers



Cover story
Pathways to a colostomy
Sarah's journey

Feature
Exercise
focus on swimming



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welcome to SPRING

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.....
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.....



The Colostomy Association have produced two NEW booklets...

Parastomal Hernias and Colonoscopy through the Stoma A Patient's Perspective

Both booklets will be available shortly...contact CA on 0118 939 1537 to order yours today.



Welcome to the spring issue of Tidings...

Sitting here on the first of the light evenings I find myself writing to you and listening to a radio programme about the Universe. The presenter is talking about journeys to known and unknown planets. You are probably thinking what has this got to do with me...well...

Recently I have been privileged to attend several events, one in Birmingham with over 200 hundred stoma care nursing professionals and two others in Chester and Huntingdon with our hugely dedicated CA volunteers. The programme struck a chord with me especially the words 'known and unknown.'

Each and everyone of the people I met at these events came together via differing pathways the ultimate focus being 'providing care' and 'receiving care to go forward and embrace life once more.' The 'known' may be seen to represent the knowledge and expertise of the stoma care nurse whereas the 'unknown' may be likened to the patient at the outset of their journey to new beginnings.

There is no doubt that those involved in the relationship of 'providing care,' specifically stoma care, are dedicated to their patients and vehemently protective of the clinical specialist services they provide. It is clear too from the many conversations I have had with patients that they are both thankful and appreciative of the excellent care received.

Both professional and patient are inseparable, both journey together displaying courage, tenacity, resourcefulness, enthusiasm and energy...the 'known and the 'unknown.'

This issue of Tidings offers several readers' stories - real life experiences with real life outcomes. There is also a specific article in our problematic stomas series about convexity from stoma care nurse Melanie Jerome RGN/CNS of the Chelsea and Westminster Hospital NHS Foundation Trust. We have the last in our series on Diet - it would be interesting to know how many of you enjoyed this series perhaps you would like to write in and tell us. The centre pages focus on exercise and keeping fit with hints and tips from CA volunteer - Bronwen Lowy and a delightful story from Sue Hatton - Executive Trustee about her swimming exploits past and present!

If you would like to comment on any of the articles featured or would like to write in with your story or the idea for an article - the Editorial team and myself would be delighted to hear from you!

Tidings can only go forward and improve with your input so if you have been contemplating writing there is no time like the present!

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

Editor
Tidings Magazine

PS. See Page 6...How to get in touch with the Colostomy Association and Tidings.

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all your regulars

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

About...the Colostomy Association

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

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

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

By telephone:
General Enquires: 0118 939 1537

Stoma care queries only:
Helpline: 0800 328 4257

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

Find us on Facebook:



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

Don't delay... Donate Online today!

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



1

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



2

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

Tidings is YOUR Magazine...

Editorial Submissions:

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

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

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

Feedback...We are always trying to improve your Magazine and welcome your feedback. Enjoy this edition of Tidings we look forward to bringing you the next edition...

How to supply digital images:

When supplying digital images for inclusion in Tidings please try to observe some or all of the following criteria:-

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

Advertising Enquiries:

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

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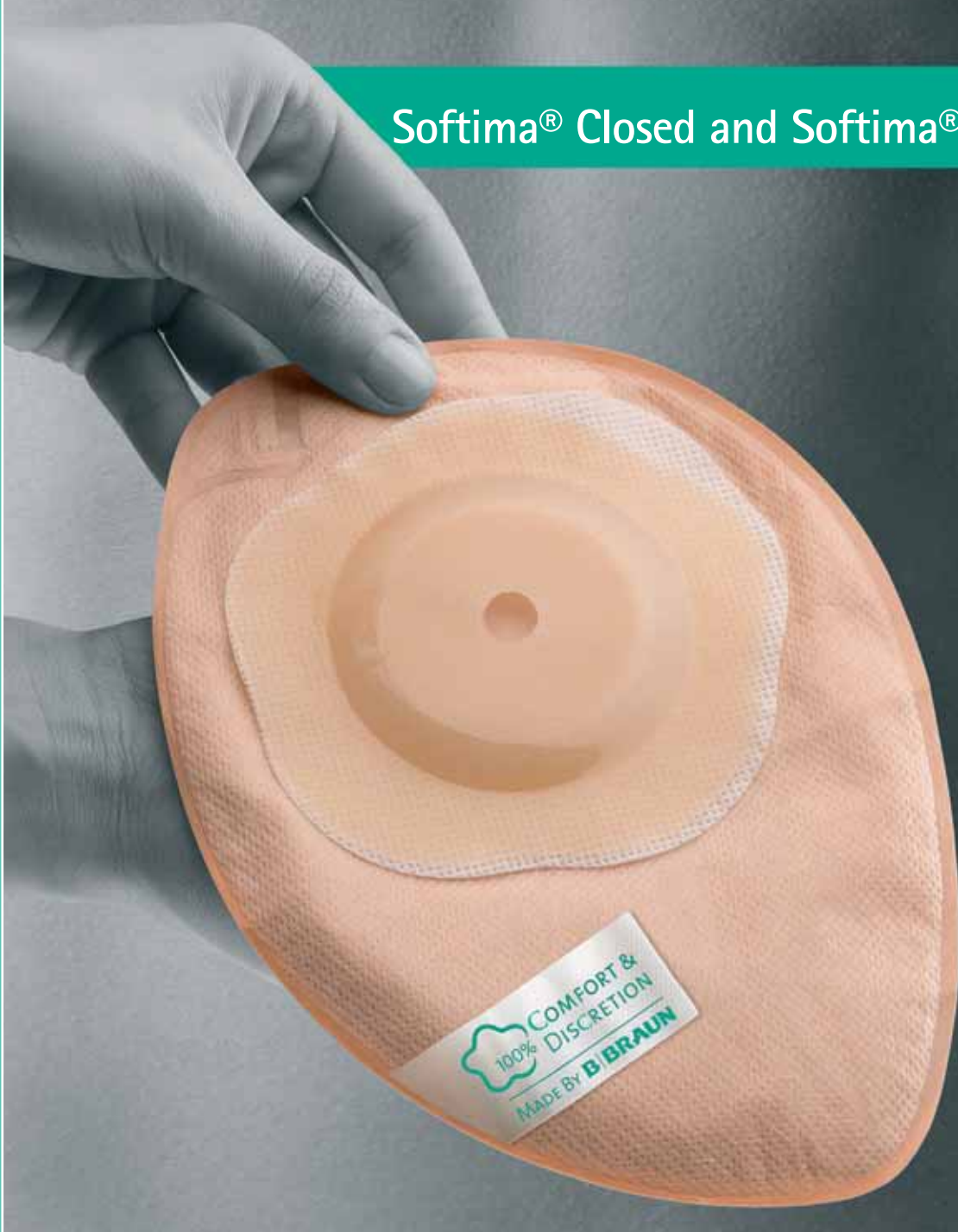
Tidings Magazine:

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

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Attention to Detail. Attention to Life.

Focus on admin at CA office...

The CA office plays a pivotal role... efficient administration and open communication are key to the work of the charity. Close contact between those in the office and those on the ground e.g. volunteers is essential to the CA's performance and ongoing existence.

Heading up the office team is Richard Bray – Office Manager (joining CA 2009). Integral to the office team are two amazing ladies who carry out their duties with passion and commitment. Both have long standing involvement with the charity (previously with the BCA and recently with CA). You may know them by their first names Gill and Jo. They are the CA office administrators - Gill Herbert (joined BCA/CA 2005) and Jo Mckenzie (joined BCA/CA 2004).

So, just what does the team tackle? Well, here's a snapshot...

Helpline...A rota of trained CA volunteers - 'Helpliners' is worked out quarterly to ensure continued 'Helpline' coverage out of CA office hours. The 'Helpline' is transferred back to the office each day from the 'Helpliner' and returned to another on the rota after office hours. The subject nature of calls is logged to enable the Association to provide relevant and up to date support materials.

Helpline telephone enquiries...to the 'Helpline' during office hours of a specific nature are referred to an experienced trained volunteer or to CA volunteer stoma care nurse Amanda Gunning CNS. A sample call – a lady calling from Dorset phoned to say her local hospital in Dorset could not perform her stoma operation (as she had liver problems). She had been referred to a specialist hospital in Birmingham – her concern was travelling back to Dorset after her operation. A worrying time, but reassurance was given and the call ended with the lady feeling more positive.

Email enquiries...are dealt with by return or if a query needs further investigation the answer is sought and followed up the later in the day or next day.

Open days...Company and stoma care department 'patient open days' are a large part of the office workload. CA volunteers are always in demand! Very often a company or stoma care nurse will request a local CA volunteer to attend their event. The office works out which volunteer is available. A volunteer is contacted and items necessary are forwarded by carrier to them prior to the date of the Open Day. This ensures patients attending have the latest CA patient information as well as the volunteer's all important 'listening ear'. The CA handles many 'patient open day'

mailings – for companies and stoma care nurses. Postcodes are supplied, labels are run and boxes of stamped envelopes are stuffed carefully with invites and placed with Royal Mail to be sent across the UK.

Other administrative areas include:-

- **Handling calls** - (upwards of 25 a day – typical call length 20-40 mins)
- **Handling and returning emails**
- **Website** - registrations/queries
- **Managing revenue** - donations, legacies, other
- **500 Club**
- **Radar keys**
- **Liaison with organisations**
- **Meeting stoma care company representatives** - to ensure CA keeps up to date with products and services.
- **Stock take/ordering and creating new patient literature**
- **Stock take/ordering general office supplies**
- **Premises and services**
- **Tidings editorial**
- **Managing incoming post** - large amounts when Tidings is published
- **Responding to requests** - sending out literature, searching and sourcing best information from Tidings issues, the internet of company literature etc.

One recent addition to the workload was revisiting the look and feel of the CA website...



The new CA website is now live

Thinking was based around the ostomate as well as partners, family and carers and the type of information needed by all.

The project began summer 2010 with discussions at Trustee and office level. The thinking was to give those visiting the site the whole picture as CA Trustee Jackie Dudley said 'to give someone visiting the site an understanding of what it's like to walk

in the shoes of an ostomate' plus an indication of what life is like 'living with a stoma' on a daily basis.

Monty Taylor - CA Chairman sourced a company who specialised in charity websites...and work began in earnest in October 2010.

A template was set up to allow content to be inserted and managed at the office. Gill Herbert was tasked with collating information from ostomates, CA volunteers, healthcare professionals and previous articles written for Tidings.

Ostomates and volunteers were asked to submit their stories for a special feature called, 'My story' (found on the home page and elsewhere on the site) the idea being to give visitors the opportunity to read 'real life' experiences which would be of benefit to fellow ostomates and those around them. Talking about the website recently Gill said, 'I would really like more people to write their

stories so that we can rotate them and keep the content fresh'.

Strangely just when Gill fell sick last summer, Sarah Wall stepped across the CA threshold as a part-time volunteer with experience in back office website technology and as Gill put it 'saved the day'. Both Gill and Sarah worked hard to get the site content and usability right. Several volunteers helped proof read the content prior to the site going live in February this year. Well done to all concerned!

Gill's comment: The Association encourages people to register on the website so that they initially obtain a CA information pack and receive Tidings on a regular basis. Invites to stoma open days events are also sent out keeping everyone in touch and up to date with what's on. We are also in the process of setting up an electronic newsletter which will go out regularly to all those who sign up for it via the website.

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...



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

CA Volunteer Lisa raises the bar...

Lisa, a volunteer with the CA works for DesignBridge. When the IT director, Jeff Hughes was replacing their equipment he let the old equipment go to the highest bidders. Lisa suggested us for the funds raised and we recently received a cheque for £556. Lisa also ran the New Forest Half Marathon in March of this year and is hoping to raise £500.

Dear Editor,

This is a donation from my Association which is in a village in Cyprus (under Turkish occupation since 1974) every year we have a dinner/dance to help the refugees' children for their Universities. When I mentioned my problem they decided to donate £200 towards Colostomy Association.

**Best of Luck,
Michael Chambi**



Dear Sirs

I have pleasure in enclosing a cheque for £165 for the benefit of your charity. This money was raised by the entrance fees for the Memorial Trophy contested by the senior members of the club and the Colostomy Association was nominated by the winner Mr Maurice Pulley.

**Yours sincerely
B Bailey
Seniors Treasurer,
Gaudet Luce Golf Club**



Dear CA,

I would like to thank everyone from the CA who are there for us Colostomates. Thank you for Tidings magazine for its reassuring comments. I would also like to thank the company Trent Direct who deliver my appliances, whose staff are very polite and very helpful and the next day delivery service is tremendous. My son Tim and granddaughter Holly did a run called Santa dash in Liverpool at the end of last year and raised £100. Family members and myself would also like to donate £50 making a total of £150 which I hope will help towards the continuation of this great charity.

**Yours sincerely,
Mrs M Bowker**



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We continue to recycle old mobile phones.

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



500 Club - Dec Draw

Mrs S H Salt	£1000.00
Mrs R Penketh	£338.00
Mrs K Judge	£169.00
Mr R Lilley	£ 84.50
Mr F W Newton	£ 84.50
Mrs M Young	£ 84.50
Mr D S Saunders	£ 42.25
Mrs S Hatton	£ 42.25
Anonymous	£ 42.25
Anonymous	£ 21.12
Anonymous	£ 21.12
Mrs E Hancock	£ 21.12

Dear Tidings,

Last year was a hectic one for me... I had a new granddaughter! I was told I needed more bowel removed and another re-fashioning of my stoma, (the 3rd attempt) moved home and celebrated my 50th birthday!

Since I am permanently wheelchair bound due to failed spinal surgery the highs and lows have taken their toll. However, my daughter arranged a party for me to raise my spirits and celebrate my 50th birthday with a small group of friends and family.

Knowing how the recession has hit both individuals and organisations I asked friends not to buy presents but to make small donations to your wonderful organisation. I am pleased to say we raised £101.20 which I hope will help towards your continued good works supporting fellow colostomates, their friends and families and carers. I have to say how much I enjoy your quarterly magazine with its informative articles which bring both comfort and support. I am pleased to help contribute, albeit in a small way, through my monthly donations and this gift from my wonderful friends.

**Yours sincerely,
Carol Edwards**

In Memory...

Mr D Garnham	£ 210.00
Mr F Green	£ 80.00
Mrs R Woodcock	£ 195.00
Mrs E Blackadder	£ 100.00
Mrs P Taylor	£ 95.00

Thank you

Join the 500 Club today to become our next BIG winner...

Dear Colostomy Association

I am delighted and extremely surprised to receive your letter this morning and its enclosure of the cheque for £1000.

I decided to join the 500 Club because it seemed a very good way of raising money for the Association but it never occurred to me that I might win a prize – let alone the top one!

Incidentally, a few days ago I completed and posted the direct debit mandate for my £12.00 annual donation and additionally the direct debit mandate £12.00 for the 500 Club. It was delayed for some considerable time due to my wife needing 24 hour care at home, items which appeared not to be urgent were put on one side and then, alas, forgotten temporarily.

However, your cheque has come at a very helpful time; sadly my wife died two months ago and it is very comforting to receive some good news. She suffered from Parkinson's disease for about 25 years and life has been very difficult for both of us for many years.

My own stoma problems have always had to remain in the background but I should like to add that Tidings Magazine has been of tremendous help to me - explaining causes of problems, especially technical ones, and, when appropriate, offering solutions. I always look forward to reading the articles and have often wished to write a letter thanking you for its publication but never seemed to have the time. In addition to the traditional help and guidance which patients normally expect to receive from their stoma nurses; the CA 'Tidings' publication makes a most valuable contribution to understanding and resolving many problems which are caused by having a stoma.

I decided to put the prize money towards the cost of a family celebration for the 'Life of my Wife' which was a very special occasion. Our three children and seven grandchildren played a major part in speaking, composing and playing music for the celebration. We hired a very large 'hall' in a local hotel and were able to provide excellent food as well as entertainment for about one hundred relatives and friends. It is a memory that we will all treasure for many, many years to come.

Kind regards to you all,
Stuart



colostomy association

Please note: Change of bank account details for the 500 Club!

The 500 Club bank account details changed in June 2010. It has come to our attention that some standing orders have not been amended and are still being paid into the old bank account. Unfortunately from 1st June 2011 these payments will no longer be included in the draw.

Please check with your bank that they have amended your standing order to take into account the new details - many thanks. **Because as they say...you have to be in it to win it!** If you have any queries about the changes, please contact the office on 0118 939 1537.

The new bank details are...

Bank:	NATWEST
Account number:	89252314
Sort code:	60-17-21

About the 500 Club...

We are pleased to announce the Colostomy Association '500 Club' giving you the chance to win cash prizes ranging from £25 to £1000. For the sum of £24 per year, you will be entered into a quarterly draw for cash prizes of £500, £250, 3 x £100, 3 x £50 and 3 x £25. At the end of each year a further prize of £1000 will be awarded. Draws take place at the end of March, June, September and December and winners will be notified shortly thereafter. Membership is restricted to the first 500 applicants so don't delay...

Simply complete and cut out the standing order mandate below and return it to: Colostomy Association, 2 London Court, East Street, Reading RG1 4QL as soon as possible.

Note: If, at the time of any draw, the club is not fully subscribed, the Colostomy Association reserves the right to distribute prizes in the proportion of the subscriptions received.

My Details:

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Postcode: _____
Telephone number: _____ Email: _____

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Account number: _____ Sort code: _____
Please pay: **NatWest Bank Market Place Reading Branch 13 Market Place RG1 2EP**
Account name: **500 Club** Account No: **89252314** Sort code: **60-17-21**
the sum of **£24.00** amount in words: **Twenty four pounds**
Date of first payment: _____ and thereafter on the same day every year until further notice

Name: (IN CAPITALS) _____
Signature: _____ Date: ____ / ____ / 2011

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

Pathways to a colostomy

A Recto-Vaginal Fistula...can be caused by trauma during childbirth, symptoms of Crohn's disease or Ulcerative colitis, or sometimes from complications during surgery



**Sarah Squire...
Research Assistant
wife and busy
Mum of two,
first contacted the
Colostomy Association
in 2008. Talking to
Bob Buckley
CA volunteer and
others via the
CA Facebook site
Sarah was encouraged
to tell her story...**

I had my colostomy surgery in 2007 when I was 34 years old, due to a recto-vaginal fistula. A fistula is defined as an abnormal connection or passageway between two organs or vessels that normally do not connect. In my case, a hole between anus and vagina, so it is more accurately ano-vaginal. These fistulas can be caused by trauma during childbirth, symptoms of Crohn's disease or Ulcerative colitis, or sometimes from complications during surgery. My cause is a bit of a mystery. I have two children, Oliver thirteen and Madison seven. Maddie was over 10lbs when she was born, and arrived rather swiftly, but nothing was apparent at the time after her birth.

In 2005 I had my ovaries removed as a precaution after losing my mum to cancer when she was just forty-five. I am told the surgery is unlikely to be the cause of my fistula but it was about six months after this I started to get symptoms. I assumed the HRT I was now taking was not quite right and I was getting breakthrough bleeding. I did what many of us do with 'downstairs business', I ignored it. After a few months I got brave enough to go my GP and was referred to a gynaecologist. By now I was mortified to admit that I thought poo might be coming through the front. The doctor reassured me I wasn't a freak, or unique and diagnosed a fistula and referred me to colorectal surgeon Ian Lindsey.

Mr Lindsey told me he would put a seton in for a couple of months and

then repair the fistula. The draining seton is a loop of plastic which threads through the fistula and keeps the tract open, to reduce the risk of infection and allow healthy tissue growth in preparation for the repair. I was told the advancement flap repair had about a 70% chance of working. Not bad odds then, I thought. The idea of the procedure is to excise a flap of healthy tissue next to the fistula, pull it over the hole, suture and 'job's a good un'. Or so it should be. Two days post op, my symptoms were horrendous. This will definitely go down as the low point in my whole journey. Each time I went to the loo I leaked poo vaginally for hours. I find it hard to explain just how awful I felt. It's not the sort of thing you tell people. It's dirty. It's embarrassing. It's wrong. After two visits to my surgeon the option of a temporary stoma was suggested. In one way the thought of a bag was a relief. But will people know? Will I be able to go to work? Will it be noisy? Will it smell?

It was arranged that I would see a stoma nurse before the op, which I was to have two weeks after the failed repair. My stoma nurse Simon Turley in Oxford was fantastic. I was convinced I wouldn't get used to it but he explained everything and I realised this was the best option for me. We were due to go to Cornwall on holiday that week and after much discussion and tears we decided my husband Steve would take the kids on holiday and I would go for the full board offered at the John Radcliffe Hospital! I couldn't go on holiday like



Sarah pictured with husband Steve and children Oliver and Madison...enjoying the sunshine together

this and didn't want the kids to miss out. It was very, very hard waving them off, but I knew they would be having fun instead of hospital visiting.

The evening they left I spent hours on the Internet finding out everything I could about colostomies. By chance I came across the Ostomyland forum. I had never been on a forum before and must admit I thought they were

for nerds. But I read and read and read. I dubiously posted a 'hello' message and was inundated with replies. One lady even had the same problem as me and was fixed, awaiting reversal. The relief to find someone I could relate to was enormous. I really wasn't a freak or unique! And you know, they didn't even sound or look like nerds! They were just normal people, with one

thing in common. They have, had, or are close to someone with a stoma. By the time I went into hospital a couple of days later I felt I had a very good understanding of life with a stoma. I actually began to look forward to it.

As it was, I had to wait a few days to get the surgery as emergencies of course took priority. My dad and his partner became chief visitors, treating me to ice cream each night I got bumped off the list! After the surgery I had terrible trouble with nerve pain, but the stoma worked well. Simon was great. That man has a lot of patience! I had a few issues with bags sticking as my stoma is flat and it seemed nothing was going to keep a good seal. But, eventually we sorted it with the help of a barrier ring.

So the family came back from Cornwall and it was time to explain to the kids just why Mum had been so poorly. They seemed to easily accept that I wasn't going on holiday with them. Too easily now I think back! But I really think kids are great accepting things at face value. So I decided to be upfront about my stoma. They took it in, had a look, and got on with life! Maddie always asked – and still does – if she was hurting my 'poorly tummy bit' when climbing on me, but it didn't seem an issue that I now 'pooed' out of my tummy. Kids really are great. Steve was, and is, amazing. I couldn't ask for a more understanding husband. My whole extended family bent over backwards to help and have been supportive all along.

Physically I was doing well. My fistula symptoms were finally gone and the stoma was OK. Now I had to think about going back to work. I work full time as a Research Scientist as part of a team developing therapies to treat Duchenne Muscular Dystrophy. At first I didn't want anyone to know, but inevitably with me being off, people asked where I was. I think the scientific environment helped me be

open. People understood the procedure and were interested in my problem and possible repairs. I lined up one workmate to take the blame if my stoma was noisy during lab meetings (which by the way, has never happened) and they were all great. It has been known for a bunch of us to crowd round a computer looking up the latest treatment options, including graphic videos! I went back to work eight weeks after the stoma surgery, and it would have been sooner if a skin ulcer hadn't knocked me back a couple of weeks. I did worry about smell, and even had Steve with his nose next to my stoma the night before I went back to work as I was convinced I could smell it! The things you do for love.

I start work early in the morning and wasn't overly happy about going off with my bag filling. I wasn't having any problems as such with the bag, but it was on my mind all the time. I had been spending more and more time on Ostomyland and had read about irrigation. It seemed very fiddly to me and a bit of a 'faff' but with the encouragement of my new cyber friends I made an appointment with Simon to have some lessons. It did seem fiddly and I did regret the chicken korma the night before while enclosed in a small space with poor Simon, but the feeling of an empty bag for hours was nice. So I decided to give it a go at home. It was a bit tricky for the first week but then I got into a routine, and it really gave me my confidence back. I felt I had finally begun to accept the stoma. I developed a hernia about six months after the stoma surgery, which for the moment is not too much of a problem. By wearing jeans it stays comfy most of the time but I do find it plays up if I am on my feet too much or wear looser fitting clothes.

Unfortunately I am now three years on and have had six failed repairs on

the fistula. Most of the time, I manage to stay positive about the situation, but I do get down, particularly as I seem to keep slipping through the system, and have to chase appointments. My surgeon was great, even when I kept turning up like a bad penny to tell him his latest handiwork had come adrift. I know they are tricky to mend, and that I have been unlucky. I have now been referred to a new consultant Bruce George, who has experience of using the leg gracilis muscle for reconstruction and I hope to have this surgery in early 2011. I'm not quite ready to give up on the fistula repairs yet and like to think I may have the chance to be reversed in the future. But as one of my good friends on Ostomyland said, 'A well irrigated stoma is often more convenient than a bum hole'. Life for me and my stoma is good. I work, I am a school governor, I travel abroad and even hope to one day repeat the Cornwall holiday I missed out on!

I have continued to visit Ostomyland on a regular basis and was thrilled to be asked by webmaster Jason to join the 'team' as a moderator. I feel I have come full circle, from being new and needing much help to being in a position where I like to think I can help out new and potential ostomates overcome their fears and problems. I was also very proud to represent them at a Colostomy Association open day along with another member of the crew Kathy. Ostomyland offers an online support community in the form of a lifestyle guide, message board and live chat. I truly believe it was through the support of members that I managed to cope so well with my stoma, and I have made friends for life. I now have a very good friend through Ostomyland who has the identical problem and the same surgeon. We like to compare notes on him over a coffee! It is also great to see the CA have a Facebook page

now. The Internet has become such a big part of many people's lives and it is good to be able to find support and advice online. Not so long ago it was easy to feel very alone with a colostomy and hopefully now ostomates do not need to look far to find someone they can relate to.

About... Recto-Vaginal Fistula

Obstetric trauma is the most common cause for the development of these fistulas. Other causes include trauma, radiation damage, and inflammatory bowel disease, especially Crohn's disease.

A recto-vaginal fistula is an abnormal opening between the rectum and vagina which allows small amounts of waste, normally contained in the rectum, to pass into the vagina leading to possible infections.

The patient complains of passing flatus (wind) and faeces from the vagina. Vaginitis and recurrent urinary tract infections may also occur. Diagnosis is made via examination under anaesthetic at which time multiple biopsies are taken.

It is possible for some surgeons to attempt to repair the fistula, although it is generally considered better to leave them alone as they can be made worse.

However, surgical techniques have improved and if problems persist giving a poor quality of life, surgery may be considered.

Direct repair of the defect or advancement of a mucosal-submucosal flap of the vagina to cover the defect is often successful. Occasionally a bowel resection with or without a temporary defunctioning stoma is required.

References:

www.crohns.org.uk
Nursing Practice: Hospital and Home
Margaret F. Alexander CBE BSc PhD RN RM RNT
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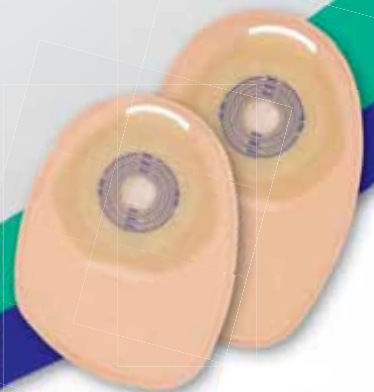
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Update on stoma care products and services

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

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"If you make plans don't tell people about them..."

Was it one of those early Greek philosophers who first said this?

As my plans involved early retirement, the sale of the family home and a move from Wales to Devon, it was only courteous that line managers, work colleagues, friends and neighbours were informed.

The first few stages went without a hitch and by mid-October 2006 we were in a mid-Devon village, taking up a six month rental on a property that suited us down to the ground. The grand plan was to use the rental property as a base from which to explore the area and the local housing market - a strategy recommended in all the best relocation manuals!

A week or so later my wife thought we should register with a local GP - a decision that probably saved my life. During the consultation the GP asked a number of questions about my family history and my recent health. 'In fine fettle,' I replied. I did briefly mention that with the recent challenges of retiring, selling up, and relocating I had felt a bit lower on energy than usual, had lost a bit of weight and my bowel pattern had changed somewhat. The good doctor that he was, he ignored my instant diagnosis for these apparently minor symptoms and promptly arranged for a colonoscopy.

On the 29th November 2006 - my 60th birthday no less and just two months after retiring - I found myself in Surgical Outpatients where I was



Eventually, after what seemed a lifetime, I was discharged on the 28th January and being at home again soon made me feel a little bit better. I must admit that in those first few days at home without the support of the colorectal nurses I found the bag to be a real challenge but as it had helped save my life I knew I had to accept its existence.

informed of the test results: there was a tumour low down in the sigmoid section of the colon and 'would I prefer to have the operation just before or just after Christmas?'

Easy decision - the consultant reckoned that as I was "young and fit", was not overweight, had never smoked and had no other underlying health issues that I would be in and

out of hospital in six to seven days and home for Christmas lunch! The impression I gained was that they thought the tumour had been caught early; there would be no need for chemo and the bowel could be re-joined without the need for a "bag". Simple!

The reality was something else. I recovered quickly from the operation

and next day I sat out in a chair beside the bed for most of the day and 24 hours later was exploring the hospital corridors – albeit grimacing somewhat with the pain from the laparotomy and the strange numbness in my rear end! I even enjoyed a bowl of soup and some yoghurt. A couple of days later, however, the downward spiral began: overwhelming feelings of nausea, loss of appetite, raised temperature, vomiting (with bile) and hiccupping lasting for hours on end. Just the smell of food was enough to turn my stomach.

Then success – or so I thought: on the 28th December after being in hospital for eleven days I somehow managed to keep down both breakfast and lunch, and persuaded the hospital to discharge me.

On the 1st January 2007 I was back in again with a suspected “leak”. Pretty obvious really as an evil smelling liquid had started to seep through the partly healed laparotomy. I knew for definite that now I would have to have a bag.

If the first stay in hospital had been a challenge then what was to follow over the next four weeks was a bit of a nightmare. A week or so after surgery my condition had deteriorated to the extent that I had to be fed intravenously; I still had a drip and catheter attached, had a drain down the nose and throat into the stomach to remove the bile, and I still needed oxygen. From being someone who had hardly had a day off work in the past 37 years I had become, over a couple of weeks, a virtual invalid. And of course there was still the underlying matter of the bag which had suddenly come into my life. Just to cheer me up, and when I was at my lowest ebb, I was given the biopsy results: the tumour was judged to be a stage “C” which meant chemotherapy!

Eventually, after what seemed a lifetime, I was discharged on the 28th January and being at home again soon made me feel a little bit better. I must admit that in those first few days at home without the support of the colorectal nurses I found the bag to

be a real challenge but as it had helped save my life I knew I had to accept its existence.

Six weeks later, once I had managed to regain some of the weight that I had lost in hospital, I started chemotherapy. This took the form of Capecitabine tablets, 500mg each and 896 in total over the following 24 weeks! I was amazed that chemo caused me no side-effects whatsoever. I did have occasional bouts of looseness but this could have happened anyway. Chemo finished at the end of July just in time for me to enjoy my daughter's graduation ceremony which, six months earlier, in one of my bleakest moments on the ward I was convinced I would never see.

September '07 saw me called in for a routine CT scan to check if anything nasty had re-appeared. The results showed no sign of cancer but did show pulmonary embolisms which meant that I was put on Warfarin for the next 18 months.

In February 2008 we moved out of our rented accommodation - the initial 6 month period had by now become 16 - to buy a house in a small town outside Exeter. Although it was in a good state of repair there was always something that needed doing and I found that having a series of projects helped take my mind off my “rotten luck”.

Meanwhile, better news began to creep above the horizon. Regular scans and bloods showed no recurrence and I started to feel more confident about the future - I remember clearly the oncologist saying at our first meeting that the first two years were the highest risk. However, any thoughts of a reversal were still far away.

Over time I became more confident with the bag and its little foibles. Holidays that had been put on hold now appeared on the radar. I have always been a totally relaxed traveller but the bag always played up when flying. On one memorable occasion when I was in the toilet having to change the bag we experienced Alpine turbulence and the “Fasten

Seatbelts” light came on! The mind boggles!

So what encouraged me to go for a reversal? The main factor was our middle child's announcement in October 2009 that he was getting married in the West Indies in March 2011. With no bag to play up the 10 hour flight would be a doddle, plus I could enjoy all those other activities that would be part of the week-long celebrations. Plenty of time therefore to go for a reversal; if it didn't work out then I could always have “Clarence”, my stoma, put back.

The surgeon confirmed that the colostomy was reversible but stressed that if the colon had become too brittle then it might not be possible. This, however, could only be assessed once he had opened me up (another laparotomy). Because I had leaked previously there would have to be two operations, one to join the colon and create an ileostomy and then, three months later, a fairly minor op to do the final connection between the small and large intestine.

I went in at the end of April for what should have been a six day stay as I was still regarded as being “young and fit” (if only). As soon as I was barely conscious I instinctively patted my left side only to discover that a bag was still there. However, “Clarence” had been converted into an ileostomy; the surgeon had rather cleverly re-used the opening for the colostomy rather than creating a new incision in my right side (the usual location for an ileostomy). So panic over!

A few hours later, however, I suffered a post op rectal bleed and this was to plague me for the next four to five weeks: standing up for barely ten minutes at a time produced an urgent sensation to “go” which resulted in an evil-smelling concoction of stale, black tarry blood and other unmentionables left over from the operation. It did clear up eventually, as the surgeon said it would, but it did mean that for the whole of May I was confined to the house and the garden.

But there were other challenges to face. The operation to rejoin the colon

low down in the sigmoid section meant that the surgeon's knife had to come very close to the nerve endings in the "waterworks department". Twice whilst in hospital I had failed to pass water so the catheter had to stay in and I obviously began to fear the worst.

With more than three years' experience of a colostomy, I had no trouble converting to the demands of a busy ileostomy. On the ward it did seem to be much sloppier than I thought it should be. When I was weighed seven days after the op I had lost just over 6kg (almost 10% of my body weight). The iron tablets to build up my bloods after the rectal bleed were causing diarrhoea; I had always thought that iron tablets produced exactly the opposite effect!

Eleven days after the op I was discharged and now began the various challenges of getting to know the ileostomy, and coping with the rectal discharge, the catheter and my concerns about possible nerve damage. Mercifully, after what seemed a very long six weeks, everything

turned out alright in the end. On the 2nd June the catheter was removed in outpatients and a successful result ensued, but only after I had downed two litres of bottled water and several cups of tea in barely an hour.

In early August the time came to rejoin my small and large bowel - an operation lasting just 30 minutes. The surgeon had warned me that, based on his experience, I could expect "thunder and lightning" for at least a couple of weeks after the reversal and on the second day after the op I did have to "go" 16 times in 24 hours, so things initially looked rather ominous. However, a day later, it had settled down to its long-term average and amazingly just seventy-two hours after the operation - and as predicted - I was on my way home.

So, after 48 months with a stoma, I am now joined up again; the bowel is behaving itself and I generally only need to visit the toilet 2-3 times a day. It has never been loose - in fact, sometimes just the opposite. I must be a contrary patient!! I still watch what I eat and take note of what

might have caused anything out of the ordinary - unfortunately my wife's fruit cake is still a "no go" area for me as is fizzy water!

I got there in the end and as they say: "No gain without pain".

Am I making plans for the future? Well, maybe, but I'm certainly not telling anyone this time around, that's for sure!

Ken Tresidder

P.S. Despite what I have endured, I would like to offer my sincere gratitude to the surgeon, his team and all the other hospital staff who have helped me over the past 4 years.. My view is that bowel surgery is a greatly under-rated area of medical expertise; it is only through the skill and dedication of experienced and dedicated professionals that I am still here to tell my tale.

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Irrigation and you...

Sue Hatton Executive Trustee writes...I can highly recommend to anyone thinking about irrigation to Google 'Colostomy Irrigation.' Two video links will present themselves. Simply click on 'Colostomy Irrigation for Bowel Cancer and Colon Cancer' and you will be automatically transferred to YouTube. Here you will find a brilliant video presented by Brian from New Zealand. If you don't use a computer, get your children to show you or your grandchildren, they and you will be fascinated!

It's good to hear from proficient irrigators that they have been teamed up with colostomates who have recently started. It is a great comfort to be able to phone someone who knows how it is done and can give first hand experience. Thank you to the stoma care nurses who are 'buddying' people up.

In the last issue, Janet Bradley queried using water from the hot tap to fill the water container. She understood that water from the hot tap was not potable (suitable for drinking). Dansac's Senior Marketing Co-ordinator, Kerry Jones sent in this reply...'It is fine to add water from the hot tap. It's a fact that hot water can contain more bacteria compared to water from the cold tap, which is why they advise that in countries where you can drink water from the cold tap, it's fine to use water from the hot tap to irrigate. However, in countries where you are advised not to drink from the cold tap, use either, still mineral water or boiled tap water when irrigating.'

Dave Gordon writes (via email): 'I have been irrigating for more than 14 years and have done a fair bit of travel in that time (three times around Europe in a touring caravan, cruises - Caribbean, through Panama, Suez down to Rio de Janeiro, the Baltic and others. He has also played pipes with the band at folk festivals in Germany and France.)

I have only once had an infection in my colon/stoma and think it was from the ship's water on the Suez Cruise. My tip, which may help others, is to carry a plastic jug with a lid in my kit and I fill it up the night before and add a sterilising tablet (obtainable from 'Boots'). I also carry a wee electric kettle which I boil in the morning to sterilise and warm up the water already in the jug. The biggest problem for travelling irrigators is

where and how to hang the reservoir. I carry a publican's optic clamp, two sizes of hooks and a roll of strong string and so far have not been stuck.'

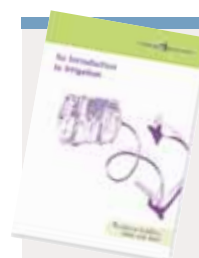
Dave recommends taking an extra piece of tubing with a connector as often the only place to hang up the reservoir is too far from the toilet. If this happens to me, I sit on a chair, next to the reservoir, with the sleeve in the plastic pedal bin. When the water has gone into the stoma, I swiftly seal the bag and move to the loo. Many irrigators prefer to sit on a chair by the loo rather than sit on the loo seat – all a matter of choice!

Dave also wishes that manufacturers could consider improving the irrigation kit. He would like to see a plastic zip along the top of the sleeve as he is still using two clothes pegs for the sleeve or irrigator drain. I use Coloplast sleeves which have the freezer bag twist to close the bag and I am comfortable with this, any ideas from anyone else? Thank you Dave very much for taking the time to write in.

A terrific letter from Hilary Spalton who had her stoma as a result of chronic Diverticulitis...She says that she was enjoying life to the full, she ran her own successful business, socialised, enjoyed going to the gym and even took up skiing at the ripe old age of 59. I have run out of space to publish her whole letter, but it is a sad journey of grim surgery and distressing life with her colostomy. She finishes her story by writing...'however, for me there has recently been a great stride forward. I decided to try 'irrigation' and it has transformed my life - living with a colostomy. I am now totally relaxed throughout the day in the knowledge that I am not going to experience any kind of horrible episode or social embarrassment.

I have a routine that takes no more than 30 mins at the end of the day and means I no longer have to wear a colostomy bag. I feel clean and fresh all the time and confident enough to do all the things I used to do without a second thought. The longer term plan is to reverse the colostomy towards the end of 2011, depending upon my general health. However, if this timescale gets pushed back I am quite relaxed about it, knowing that my life is no longer ruled by my condition and that there are many more things to enjoy again.

Sue writes: I am hoping to have a hip replacement in March. I have had it postponed four times due to shortage of beds, infections and my surgeon being ill. This will be the fifth time that I have been in hospital for surgery since my colostomy, knee replacement, gallstones, broken leg and broken ankle! I have had to cope with blockages caused by the painkillers and have found that drinking copious amounts of water and having an extra irrigation have helped to shift the offending hard lump of poo! It will be great illuminating the surgical staff about being a colostomate who irrigates!



Editors Comment

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

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



Courtesy of South Devon Healthcare Foundation Trust

In her third article for Tidings - Sophie provides advice on how to regain lost weight. She considers why some ostomates may find this difficult and suggests solutions.

Regaining lost weight...

During periods of illness or hospitalisation many people find they have lost weight. This can be more of a challenge to regain if you have a stoma, particularly in the early stages when you are still getting used to day to day life with a stoma which can be unpredictable.

Many people find that their body image has changed following formation of a stoma and struggling to regain lost weight and fit into your normal clothes again can contribute to this problem. Appetite is often affected which makes increasing your intake more of a challenge.

You may also find, particularly if you have been very unwell, that, although you are eating the same as usual, you still can't regain lost weight. This is because during times of illness additional nutrients are required to fight infection or disease. This will mean that you require additional energy and protein just to maintain your normal weight which can be a struggle.

It is important that you aim to maintain your Body Mass Index between 18.5 - 25kg/m² to ensure good long term health and a full recovery from your surgery. If your BMI falls below 18.5kg/m² you are at greater risk of problems such as

delayed wound healing, muscle weakness, malabsorptive problems, low mood and lethargy.

This article aims to give you a few ideas on how to regain lost weight whilst accommodating for your stoma. If trying to increase the volume of food you are eating is difficult due to your appetite or stoma function, eating little and often is helpful.

Fortifying your foods with extra calories and protein without adding bulk is a great way to make every mouthful count.

Try these simple food fortification ideas:

- Add 2-4 tablespoons of skimmed milk powder to 1 pint of full fat milk and mix well. Use this as you would ordinary milk. If you don't like full fat milk, semi-skimmed milk can be fortified in this way
- Have milky coffee or hot chocolate made with the fortified milk instead of tea or ordinary coffee
- Add butter to vegetables
- Add grated cheese or double cream to soup, casseroles etc
- Snack on crisps, biscuits or cheese and crackers throughout the day
- Add honey, syrup or sugar to cereal or porridge
- Make smoothies with fresh fruit, milk and ice cream or full fat yoghurt

- Have plenty of butter, margarine and mayonnaise or salad cream in sandwiches

- Aim to drink one pint of fortified milk or full cream milk per day

If your appetite is the main problem, try some of these tips for overcoming a poor appetite:

- Do not drink with your meals; this can make you feel fuller quicker and make food rush through your bowel too quickly
- Try cold snacks rather than hot; they can be easier to manage if it takes you a long time to eat as you will not have to reheat them
- Try to have your favourite foods available at all times to tempt you
- Smoking decreases appetite so try to cut down or stop if you can
- Try placing the dining table near a window or eat with other people to make meal times more pleasant
- A small glass of wine or sherry, or a measure of spirits, half an hour before a meal can help to stimulate your appetite - check with your doctor or nurse first that alcohol can be taken
- Preparing foods can sometimes be too tiring so keep available a selection of foods which require minimal preparation such as ready meals or convenience foods
- Remember, having something is always better than going without

Foods which are good for gaining weight and patients report help to control loose stools include:

- Low fibre biscuits
- Arrowroot biscuits
- Rice pudding
- Ripe bananas with custard or yogurt
- Mashed potato with cheese
- Smooth peanut butter
- Jelly sweets
- Marshmallows

If you have not managed to increase your weight by fortifying your diet or increasing your intake, your doctor, specialist nurse or dietitian may have prescribed nutritional supplement drinks such as Fortisip, Ensure Plus or Fresubin Energy. These can be useful if you are struggling to regain lost weight as they provide you with energy and protein as well as vitamins and minerals in a small volume. There are similar products such as Complan and Build-up available from large supermarkets and most chemists.

Here are some tips for helping you to take your nutritional supplements:

- Add lemonade or soda water to Juice style supplements to dilute them
- Add extra milk to Milkshake style supplements
- Serve over ice
- Split into 50ml 'shots' and take at regular intervals
- Add to puddings and hot drinks; 'neutral' flavoured supplements can be added to sauces, soups and casseroles
- Blend with ice cream for a delicious milkshake
- Most importantly, they are always best cold from the fridge

If you find that increasing the fat in your diet increases your stoma output and this becomes unmanageable it is important that you discuss this with your stoma specialist nurse or your doctor. They may suggest anti-diarrhoeal medications, thus allowing you to continue improving your intake. Try taking starchy carbohydrates such as rice, pasta, bread, crackers/biscuits with the high fat foods; this may help you to tolerate them better.

If you are continuing to have problems gaining weight, or you follow other dietary restrictions that conflict with the above advice, and you are concerned please contact your stoma nurse who may refer you to a dietitian for advice tailored to your needs.

And remember, if you feel that your diet is very restricted and you are struggling to increase the variety, it is a good idea to take a good quality multivitamin and mineral supplement daily. If you have any concerns about this please speak to your doctor or nurse before doing so.

Your diet questions answered...

Q: I read your article in the winter edition of Tidings with interest, but what sort of diet would you advise for a patient, like myself, with both Type 2 Diabetes and a Colostomy?

On being referred to a dietitian I was sent to either one in the Diabetes Clinic or spoke to one specialising in Stoma Diets on the General Surgery ward. Here lies the problem – neither of the dietitians were able to provide a diet that was manageable for a patient with both conditions.

Also, like many Ostomists, I experience problems digesting vegetables/fruit and fibrous foods, in my case possibly due to adhesions resulting from many surgical procedures on my stomach, or food intolerance. This results in severe cramps leading to vomiting or loose 'output'. Whilst I try to eat a 'healthy diet' I have to watch out for those foods that aggravate this condition whilst trying to get my BMI down

A: Thank you for your question and I'm sorry to hear you've had problems getting the help you need. Unfortunately, without a lot of additional information it is very difficult for me to give you any more specific advice. As outlined in my previous article, it is still possible to successfully lose weight with an ileostomy or colostomy following a low fibre diet. However, I appreciate that it may be more difficult to control your blood sugars if you are eating low fibre carbohydrates to control your

obstructive symptoms. You may find that increasing your physical activity aids both your weight loss and blood sugars and is obviously very beneficial for long-term health.

If you need further advice from a dietitian I would suggest you call your local dietetics department and ask to discuss your needs with the Lead Dietitian to identify a dietitian with the appropriate skill mix to help you.



Reverse Gear...

In the last of her three articles Susan Fifer tells us about her reversal and how she feels now....



I've just phoned the Colostomy Association to ask if I need to return the RADAR key I bought 16 months ago. The reason? My reversal in October was successful and I am now bagless. Since I shared how I felt at 10 weeks and 10 months as a colostomate, I thought I might finish with some thoughts on the reversal process.

I realise, of course, that there are many for whom a reversal is not a possibility. Even in situations where you are told that your colostomy is temporary, having further surgery is probably not the main thing on your mind when you wake up in intensive care with your first bag attached. The surgeon informed me that a reversal was possible but could only be considered after several months. My body had to settle down from its two bouts of major surgery, and chemotherapy was on the horizon.

In theory, therefore, there was plenty of time to think about it but I kept pushing the idea away. Why? Well, as ever, there were other things to deal with. Chemo for one and the bag itself for another. I got used to having a bag. If a reversal wasn't possible, I wanted to see the colostomy as, if not exactly desirable, then at least as something I could incorporate into my life and routine. I read lots of posts on colostomy websites and found that, as with all things in life, expectations, experience and reactions varied widely.

This was also true when I read about the experiences of those who have had a reversal or were considering this surgery. Some had found it a breeze; others had horror stories to tell. When my surgeon first suggested that I could now consider a reversal, I suppose it was the horror stories that were uppermost in my mind – I do have a very active imagination. I wrote down lists of the pros and cons of surgery and the possible outcomes: reversal impossible; temporary ileostomy; another leak into the abdomen (cause of the original colostomy).

Strangely, the one scenario I didn't rehearse in my head when I woke up in the small hours was that the operation might be successful. This was despite the reassurances of the consultant and from someone I know who had undergone this surgery a number of years ago. Perhaps I didn't want to wish too much for success in case I jinxed the process in some way and upset the deities dealing with colonic matters. When it's happening to you, no amount of philosophy and rational thought is going to help.

It was my brother who helped me to accept the process (though he probably doesn't know the effect his words had on me.) He said that I'd go through with it because I would look on it as a challenge or as an adventure. I was a bit dubious about this analysis at the time but did eventually decide that this was as good a way to look at it as any other.

I had forgotten what a pain abdominal surgery could be (in more ways than one.) I do remember waking up in the recovery room and asking groggily whether I was still in possession of a bag. No, I was told. I'm not sure now how that felt – disbelief, relief, crossness with myself that I had worried needlessly about the outcome. As usual, a whole mixture of feelings.

Recovery in hospital had its ups and downs. I was there for eight days and

had support from the stoma and specialist colorectal nurses. I was given a stool chart (in colour) so I could record output. As I reported to a nurse after the first happy event "The eagle has landed." Unfortunately, she was a little too young to recognise the allusion to a momentous event but that didn't stop me suggesting that laminated stool charts could become a talking point at dinner parties. I realised that I was going to have to moderate my excessive new found enthusiasm for going to the toilet. There are some people with whom you can discuss these things and others who definitely see it as too much information.

Coming home was like a repeat of last year but with a much more upbeat feel – no chemo ahead, no decisions about surgery to be made. I kept a diary for a couple of weeks detailing bowel movements and my food intake. My fear (of multiple daily visits to the toilet) was unfounded. Things settled down quite quickly and now it's once or twice a day, just like it was before this all started. I've donated my spare supplies to the stoma nurse, dismantled my supplies trolley and got rid of my nappy bin through Freecycle. I have quite a lot of scars (from previous as well as recent operations) but, since my bikini-wearing days were over many years ago, this is not likely to be a problem.

Even the bad weather around Christmas didn't worry me. I had opted for surgery at a time when I was unlikely to want to go out. Even when I started to go stir crazy from being indoors all the time, I knew that it didn't really matter. After all, half the country was stranded indoors by snow and the other half was stranded at airports or on motorways. And I could start worrying about other things, such as, did I need to return my RADAR key.

Susan Fifer

Research has shown that regular exercise no matter how insignificant can be of real benefit to everyone...today we are encouraged to get out there and do our daily 30 minutes. Deciding what type of exercise will suit your lifestyle can be a problem...however the next few pages may give you some ideas...



Exercise...how about it!

Bronwen Lowy CA volunteer explains the benefits...

So, what are the key benefits of regular exercise...

- Improved mobility and keeping your muscles strong.
- Improving your sense of well-being - may help to reduce feelings of stress or depression and make you feel more confident.
- Can help to reduce the likelihood of becoming overweight or obese.
- Helps prevent some illnesses and boosts your immune system.
- Reducing your risk of developing heart disease, type 2 Diabetes and osteoporosis.

Exercise not only improves your physical health, but also improves your sense of mental well-being. Regardless of having a stoma or not, you should aim to do at least 30 minutes of moderate (non-intensive) physical activity five days a week.

Moderate exercise can include going for a gentle walk, or doing some gardening. However, if you have been inactive for a long period of time, try to build up to 30 minutes a day over the course of several weeks. Also, avoid high-impact exercises, such as sports that involve hard jolts to your body, for example football or squash.

Always start an activity slowly and gently, warming up before you start and cooling down at the end. Remember to drink plenty of fluid – try to take regular small sips as this helps to keep you better hydrated.

Whatever you choose to do, start slowly and steadily, trying not to overdo anything, until you find a level you are comfortable with. It may be worthwhile seeing a professional instructor in whichever sport or physical activity you would like to be involved with. Some gyms have

specialist programmes for people recovering from surgery or with specific types of illness, disability or medical condition. You may wish to discuss this with your GP, Practice Nurse or Stoma Care Nurse, as they may be able to refer you onto one of these schemes.

Please remember to always ensure that you have checked with your medical practitioner before you commence any type of sport or physical activity.

Pilates can be especially suitable for ostomates as the exercises can be fairly easily adapted to suit the individual and can be very gentle and non-threatening. This type of exercise is particularly good for developing stronger abdominal muscles, which in turn helps keep your back strong and can sometimes help in preventing an abdominal hernia.

Check out your local leisure centre (details can usually be found on your council's website) as they will have a whole list of things you can try. Your local Primary Care Trust may have a list of health walks in your area – a great way to get fit and meet some new people.

When you feel the time is right for you to start exercising, I am happy to talk to you via email or phone. I can be contacted via the Colostomy Association on: 0118 939 1537. (I am also happy to talk to any fitness professional that wants to know more about exercise and stomas).

Whatever you want to try, keep to a few simple rules...

- Check with your GP or SCN before you commence any exercise programme.
- Start slowly
- Stop when you've had enough.
- Enjoy the experience!
- Don't feel intimidated.



Focus on Swimming...

Swimming and Aqua Aerobics are considered great all round types of exercise and activity to keep you fit and healthy. Sue Hatton shares her past and recent swimming experiences with us

I have always loved swimming. I spent three idyllic years with my parents in Singapore from the age of 9 and every day I was in my bathing costume (as they were referred to 50 years ago). I then went to boarding school in Ashford and early in the summer term, we were required to leap into the unheated pool and thrash up and down before emerging dripping, freezing, lips blue with cold. I cannot imagine any schoolgirl doing that now.

There were outdoor lidos. I have a very fetching photo of me in a bikini aged 19, posing at Guildford lido. I was a young officer cadet and thought this lime green, towelling creation was an eye-catcher – ah...those were the days! Then marriage and 3 daughters later and the figure fell into a vastly different shape, but I still swam with the girls and loved the occasional warm seas of holidays that we saved for. Then the girls grew up and I had a sedentary job and the weight piled on and I made every excuse not to find time to exercise.

So aged 46 I had bowel cancer and for 2 years until my stoma was formed, I didn't go out much and I could not have considered swimming more than I could think I could fly. However, my husband Neil and I began to think about holidays abroad, we went to Cyprus and rented a 'villa' (they call all properties villas, this was a 2 bedroomed bungalow, and it had a pool).

What heaven it was! I had the same costume that I wore in my early 40's, very threadbare around the rear, but it didn't matter, no-one could see me and my husband was delighted that I was splashing around in the water.

I irrigated every morning, but I could not get on with plugs, or small caps, so I swam with my usual one-piece pouch. It was fine and the adhesive didn't peel off in water. I had quite a selection of bags with me as I always collect samples from Patient Open Days and enjoy trying on different makes for different days.

Now 14 years on arthritis has set in. I have had a knee replacement and, if my hip is to be replaced, I have to lose weight and get fit. For some reason, I could not get my head around going to the local pool, but having grandchildren changed all that!

Katy came to stay with Orla (aged 3years) and Amelie (aged 18months) and Granny needed to help with Aqua Shrimps. Somehow, helping with little ones and having the attention taken off me, made it easier to cope with the communal changing room. Who on earth is watching a Granny get changed! I had put my costume on at home. You may be glad to know I had been given a new one, floral and ruched over the tummy, (plain ones tend to show the outline of the stoma bag). It was wonderful to be splashing around with these two little girls and I loved every minute in the water even

doing aqua fit aerobic exercises that I had learnt in enthusiastic times in my 30's.

As we were leaving the pool, the next session of swimmers were arriving. They were mostly disabled, people with strokes, on crutches or overweight. My daughter asked what they were doing, and we were told this was the Action Leap, a free class for anyone who wanted to get fit but had some form of disability. She suggested that I stay on and join in while she took the girls to the swings.

That was my first introduction to Helston Pool. Now I try to swim at least twice a week with the over 50's. I am a typical 'head clear of the water, hate getting my hair wet, breast stroke swimmer', but my brother sent me goggles and a nose clip and told me to get crawling as I won't be able to breast stroke when I have my hip done. It was really liberating to get my face under the water and to try the crawl.

When the ladies from this disabled group all returned to the communal changing room to strip out of their swimming cossies, there were three who had stoma bags! No one was embarrassed though I still preferred to strip off under my towel. Skirts are easier than trousers I have discovered and my 'crocs' have been ideal for slipping on and off my feet. One lady has sewn 2 towels together leaving openings for her head and arms and she neatly divests herself of her wet gear with complete modesty.

I have since found myself a 'boyfriend', Brian, who had his hip replaced last year. We stop after 5 lengths to pass pleasantries on the state of our joints! We are infuriated by the ladies who gossip and take up three lanes, which we have to skilfully negotiate, but there is a lot of smiling and quick chats.

I will not be able to swim for three months after my hip is replaced, but look forward to rejoining my group when I have the new hip and don't have to hobble; maybe I deserve a new swimming cossie to go with the new 'Me'!

Choosing and Buying Swimwear...

There is no doubt that the high street offers the ostomate interested in swimming variety and choice. But do the garments available really have all the answers?

The following is a list of criteria important to ostomates when looking for swimwear...

- functional attractive designs
- built-in discretion and disguise
- comfort and added support
- security options for confidence
- high waisted options

Here are some Top Tips... to help you find your perfect swimwear...

For ladies...

- Choose swimwear that makes you look good and feel confident. Go for a one piece with or without straps.
- Choose patterned fabrics as opposed to plain ones which will help disguise your pouch.
- Check out the material (Lycra) to ensure a good fit that is both comfortable and supportive and will keep your pouch in place.
- Choose swimwear with a ruche panel and lining or double layered fabric to the front which will help support your pouch.
- Try a two-piece Tankini some are now available with high waisted shorts.

For men...

The main consideration for men when choosing swimwear is the position of the stoma.

Specialist suppliers make trunks that are 4.5cm longer from crutch to waist, than high street retailers, which avoids the waistband cutting across the stoma and keeps the pouch hidden.

- Go for patterned fabrics as opposed to plain ones.
- Look out for high waisted trunks e.g boxer or boarder style.



- Check inside the trunks as some have internal pants to give extra support and privacy.

- For security look for trunks with a wide elasticated waistband and drawstring.

If you are worried about your pouch becoming detached whilst swimming buy a specially made swimsuit or pair of shorts with an integral security pouch.

For children...

- Let them choose their swimwear under guidance this will give them added confidence.
- Check out the Hi Line swimming range - 'Swimwear for Special People' from OstoMart. The swimwear is manufactured with a secure integrated waterproof pant which helps contain any accidents.
- Also check out Tankinis or one piece swimwear for girls and high waisted trunks for boys.

Here is some advice that you may find helpful when swimming...

You could try wearing a smaller stoma bag under your swimming costume or trunks as these can be more discreet.

HEALTH EXERCISE

Filters on your appliance can work poorly or not at all once they're wet or damp. Some ostomates tape the flange edges, some don't. If you have a filter on your appliance this should be taped so water doesn't damage the filter. If you've changed your flange before swimming it's a good idea to wait an hour before going swimming to make sure it has adhered properly.

Your stoma care nurse will be able to advise on the many different varieties of appliances available. If you are worried about damaging your stoma whilst swimming, although this is unlikely to happen, you could try wearing a stoma shield.

Remember that the great majority of 'normal' people have lumps, bumps and imperfections on their bodies - very few of us are model perfect in the first place - and nobody is going to be staring at you.

(NB: It is recommended to avoid swimming in artificial pools, spas and the sea for at least six to eight weeks or until your wounds are completely healed because of possible infection.)

Buying swimwear specifically designed for ostomates may give you more comfort and confidence. Here are a few specialist manufacturers and suppliers....

• **Comfizz** - Waistband support wear that can be worn under regular swimwear for that extra layer of security.
Contact: 0113 289 6876
www.comfizz.com

• **Cuiwear** - Ladies available in sizes 8 – 24 Gents (one style only) sizes sm – xxl. Call for full colour brochure.
Contact: Tel 0800 2792050
www.cuiwear.com

• **Glitter Beach** - Ladies swimwear designed by an ostomate.
Contact: Tel 01505 843306
www.glitterbeach.co.uk

• **OstoMART** - Ladies swimwear available in sizes 10 – 24 Gents available in sizes sm – xl.
Contact: Tel 0800 220300
www.ostomart.co.uk

White Rose Collection Ltd - Ladies available in sizes 10 – 22, one piece swimsuits and tankinis in varying designs and colours. Gents available in 32 - 48 'White rose collection' and 'Just Men' catalogues available
Contact: Tel 01202 854634
www.whiterosecollection.com

• **Vanilla Blush** - Ladies and Gents underwear and swimwear, also ladies bridal lingerie.
Contact: Tel 0141 7630991
www.vblush.com



SASH

- The Sash belts are available on prescription and suitable for both male and female.
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- For further information and to obtain an Order Form Freephone : 0800 389 3111

Security and Leakage Belt



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



"the ring of confidence"

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

Ref. no. SR103

Sash Medical Limited

"Woodhouse", Woodside Road, Hockley, Essex, SS5 4RU.

Stoma Support and Hernia Belt

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



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

Ref. no. S1

Freephone 0800 389 3111

Website:- www.sashstomabelts.com

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

For more information:

SASH Woodhouse Woodside Road Hockley Essex, SS5 4RU England

Telephone: 0044 (0) 1702 206502 Fax: 0044 (0) 1702 206502 Freephone: 0800 389 3111

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Breakaway...bringing families and children together building confidence for the future...



2011 got off to a flying start with a Christmas party in January! We were all set for well over 100 people attending our Christmas celebrations but unfortunately things didn't go quite to plan as mother nature laid a carpet of deep snow on the ground, snow continued to fall and so we were unable to get the youth hostel in the peak district.

Eventually, we did all manage to get together in January even though the event was somewhat delayed. We welcomed many new families and returning families. Speaking to a Mum and Dad who were feeling a little lost – as they had just heard that their son was going to require a colostomy – I invited them along to our weekend to meet other parents who I knew would give them support and reassurance.

The children enjoyed climbing Thorpe Cloud...they call it a mountain and I have to agree but technically it's a VERY big hill! They climbed the stepping-stones over the river to get there. They made and launched rockets. Sang Christmas carols with one of the Breakaway Dads playing

his Cornet and enjoyed a yummy Christmas Dinner...it didn't matter that it was January they were there with their very special friends and great fun was had by all. Needless to say Father Christmas delayed his return to the North Pole until he had visited our very special children and delivered their presents...what a good chap he is!

Julie Bastin
Chairperson
Breakaway Visits

Will's parents Mel and Ian share their Breakaway experience...

It is difficult to put into words what becoming part of the Breakaway family has meant to my husband and myself but I shall try... Our youngest child Will has just turned 9 and has always had faecal incontinence/constipation problems. After years of being told 'it's a boy thing' we were referred to a Paediatric Gastroenterologist and found ourselves at Great Ormond Street Hospital (GOSH). We were incredibly lucky to see a consultant who assured us within 30 minutes that Will did have a problem and that he would get to the bottom (!) of it. True to his promise he has left no stone unturned and we have the utmost faith in him.

We spent two years in and out of GOSH undergoing numerous pressure tests, biopsies, MRIs and medical treatments, the results confirmed that Will has no function in the last 25-30cm of his bowel, rectum or sphincter. His last set of tests finished December 2010 and confirmed that there were no medical options left and that he would need surgery to hopefully form a functioning bowel which would mean a colostomy followed by an ileostomy while the surgery is ongoing. We came out of

GOSH on 17 December and threw ourselves into Christmas. Christmas passed, and then it hit, it was like a bulldozer...our son required major surgery, leading to a colostomy, he was 8, what will his friends say? How will we tell him? How will we cope? WE FELT SO ALONE.

We decided to learn, learn and learn about it and our first stop was the Colostomy Association. The Association and Tidings have been a wonderful source of help and information. We have been receiving Tidings since the end of 2009 and have learned a huge amount from the articles and samples enclosed etc., our remaining and major problem at the time was emotional...fear and isolation. It was the Colostomy Association who signposted us to Breakaway and Julie Bastin - Chairperson of the charity.

Julie contacted me via Facebook, then she texted, then she messaged me again and she carried on...listening to me crying on the phone (crying is a regular thing, happy or sad, I'm a crier!) she put up with my waffling. She was in Derby; we were in Kent and feeling incredibly isolated and lost. Julie then invited us to the rearranged Breakaway Christmas party weekend in January, just us as parents, to spend some time with people who were already in this world we were entering, to show us we were not alone, to show us there were people we could talk to.

Every mile we drove further north to Ilam Hall I got more nervous, even a glass of wine in the pub where we had dinner (because we hit so much traffic) didn't calm my nerves. We arrived to be greeted by a wonderful madhouse of kids running everywhere, Julie giving us name badges and keys, people all milling around chatting and laughing. It was so overwhelming, I wasn't ready, and I wanted to go home and most of all I felt like I was intruding. I was sitting in

the lounge with Ian trying to calm me down when a lovely lady called Denise noticed I was trying to hide the fact that I was crying, she came over and asked if I was OK. As did someone else, then someone else, then someone else, then Julie came and asked what was up and was introduced to my repetitive crying! That was it: to say we were welcomed with open arms doesn't come near to describing the truly amazing way we were enveloped in kindness and understanding.

We were astounded. We just sat and chatted to people who knew how we felt, how scared we were, who had been through the tests, the surgery, the telling the kids, the tears, the worries and who had learned to deal with various stomas and the like. We met people who felt just as lost and isolated as us – who could support us. We couldn't believe that over lunch the next day we could just say, 'Oh, does he have to have a special diet?' 'How do we dispose of stoma bags?' in between talking about Eastenders or whatever – we fitted in – we were part of the Breakaway family!

By Sunday morning we left as totally different people - I was even dishing out details of a product I read about in Tidings to someone! Kisses all round, Facebook friends added... incredible.

When we left Ilam Hall we still hadn't told Will about his surgery, we were waiting for a stoma nurse to do it with us because we had no idea how to tell him. Thanks to the confidence we received from attending this Breakaway event we told him all about it the day after we came home and I have since given an hour and a half talk to 30 kids in his class! There were several community stoma nurses who attended the weekend, the most wonderful nurse who works out of our local hospital has since become Will's community nurse who he adores. Unbelievable.

Our family members cannot believe the change in us both since we came back, we are still nervous but one thing is different – we now know we are not alone – the strength that Breakaway brings us is immeasurable – thank you to all concerned.

26th August 2011 for 3 nights YHA National Forest Derbyshire. * Spaces still available*

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Revolutionary elastic adhesive innovation offers life-changing solution

A recent international survey of people with intimate healthcare issues uncovered the full extent of the difficulties and personal challenges they face every day of their lives...

One of the largest of its kind ever conducted by Coloplast, the Ostomy Care survey included feedback from over 500 nurses and some 1686 people with an ostomy, both male and female - 660 were colostomates.

Themes covered in the survey included:-

- Experiences during hospitalisation
- How training in daily care of the stoma was perceived
- Contact with stoma care nurses
- Social and emotional challenges connected with living with a stoma

The survey revealed that almost 60% of people with a stoma have problems fitting a stoma appliance securely to their skin. The difficulties are usually due to one or more individual body issues such as scarring, skin folds, uneven skin surfaces around the stoma and hernias. Securely fitting an appliance to uneven surfaces can be a constant worry. Weight issues often add to the problem.

For many people, living with a stoma means constant concern and insecurity. For some – as many as one in three, according to the survey – the everyday problems of leakage, skin irritations and the emotional challenges are faced without talking to anyone about them.

Key findings from the survey revealed:

- 57% of people with a stoma have problems fitting appliances to their skin
- Over 50% of people who have been living with stoma for five years still experience leakage, skin irritations and other problems that impact on their lifestyle and personal well-being

- One in three people who experience personal difficulties suffer in silence, unable or unwilling to share their anxieties with others

Feelings of insecurity caused by poor body fit and leakage can have significant social and psychological effects.

Senior specialist stoma care nurse Carol Katté says that body fit is a serious issue. "I can certainly appreciate the views of those who find living with a stoma challenging. For some it is a major life event." Carol who works with the Ashford and St Peter's Hospitals NHS Foundation Trust in Chertsey, Surrey sees 200 new stoma patients every year following ostomy surgery.

According to the survey, leakage is the main concern for 60 per cent of people during the first six months after leaving hospital. Even after five years 53 per cent of people living with a stoma still experience similar problems.

"There are people who do suffer in silence which is why it's important to maintain regular follow-ups," says Carol. "However, even in the UK, where we have very advanced stoma care nursing services and access to good stoma products, it is not always possible."

Colostomate Vanessa Denvir agrees that concern about an insecure body fit and fear of leakage can impact on – and in some cases ruin – people's lives. "It destroys their confidence in themselves and a lot of these people don't socialise or have a fulfilling private life because of their insecurities," she says.

Vanessa appeared on Channel 4's Embarrassing Bodies programme to talk about her own experiences as a colostomate. She has also spoken at

national conferences about the physical and psychological challenges involved.

Responding to the survey findings, Coloplast is preparing to unveil a technological breakthrough which could make all the difference to people living with a stoma. A new, unique colostomy product – SenSura® Mio – features a revolutionary elastic adhesive that is designed to improve body fit and reduce the risk of leakage.

Combining elasticity with the benefits of modern stoma care adhesives creates an adhesive that is both flexible and adaptable to individual body circumstances. Crucially, it maintains a secure fit between the stoma bag and the stomach even where there are skin folds, hernias and scarring. Designed as a life-changing ostomy appliance, SenSura® Mio will be available from mid-2011.

This innovative stoma care solution may well improve the lives and reduce the challenges of colostomates and other ostomates 'living with a stoma' providing renewed confidence to start enjoying life again.

As Vanessa states, "Anything that helps to restore people's confidence and which will hopefully change their lives for the better has to be good news."

Editors Comment

To find out more about SenSura® Mio visit: www.coloplast.co.uk where anyone interested in using the new product can register their details

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For more information, please visit sensuramio.coloplast.co.uk



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www.coloplast.co.uk

Update from S.C.A.R Stoma Care and Recovery... plus an appeal from Hospices of Hope

Way back at the beginning 2004, SCAR launched an appeal for surplus stoma care appliances to send on to those desperately in need in third world countries. The response was magnificent!

For a few years SCAR were able to help send supplies via various well know charities. Sadly though their help began to fade and they were left struggling to find a means of distribution.

SCAR is a very small self funding charity but it was important to them to keep accepting all parcels that came into them as they had decided to sponsor a young lady in Uganda and were determined to continue!

More and more parcels arrived and it soon became clear that they needed to find another route for the surplus that had accumulated. Last year Tidings Winter issue 2010 featured an article called Spare Ostomy Supplies which outlined the work of Hospices of Hope and also appealed for stoma supplies and related accessories to be directed to them.

SCAR contacted Hospices of Hope and arranged a meeting with their Scottish Director who was happy to take on stoma care supplies.

SCAR would like to acknowledge all who have kept the charity going and would like to send a big THANK YOU to those who sent in their spare supplies.

SCAR would also like to ask you to send any spare drainable bags directly to them for their young lady in Uganda. And to send any colostomy closed bags or urostomy bags to Hospices of Hope.

For more information about the work of SCAR please contact:

Maggie Littlejohn - Organiser
Stoma Care and Recovery (S.C.A.R.)
1B Redburn Gate,
Irvine, North Ayrshire KA12 8TH
Telephone:
01294 271060 or 01294 557478
Email: maggie13@sky.com

An appeal from Hospices of Hope:



"Can you help us supply 72,000 stoma bags this year?" That is what our Moldovan partner Hospice Angelus is asking. In the poorest country in Europe they try to provide 200 patients with 30 stoma bags each per month in Chisinau, the capital city. The Ministry of Health in Moldova sees the dedication of its doctors and nurses and knows that patients need help. Currently they are making use of surplus British stoma bags to provide pioneering stoma care.

If you can supply new stoma bags, please send them to Hospices of Hope, 28a High Street, Otford, Kent, TN14 5PQ.

If you need help with transporting them, please ring Barbara Merron on 01959 525 110 or email Barbara at barbara@hospicesofhope.co.uk

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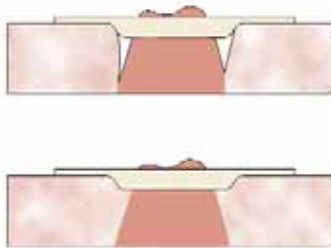
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Problematic stomas... Convexity

Written by
Melanie Jerome RGN, Bsc(Hons), CNS
Chelsea and Westminster Hospital
NHS Foundation Trust

What is convexity?

The term convexity, or a convex pouch, refers to pouches that have a baseplate (flange) that curves or bulges outwards rather than being flat as on a standard pouch. All the leading stoma manufacturers produce a convex version of both their drainable/closed and 1piece/2piece pouches, although they can vary in the strength or firmness and the depth of the convexity.



Why would I use convexity?

Convex products are recommended for use by stoma care nurses usually in response to difficulties such as stomas under skin folds, in dips, skin creases and retraction.

These difficulties can often lead to an unstable appliance, leakage and the associated sore skin.

The convex base plate has a circular 'hump' or ridge built into it which, when worn, has the effect of putting a ring of gentle pressure on the skin around the stoma. Often creases can be 'ironed out' and dips can be filled with a convex baseplate, thus increasing security and preventing leakage. Stomas that are mildly retracted can be encouraged to

protrude into the pouch, with deeper, firmer convex products being used on stomas that are more severely retracted. Also, as the convex baseplate is sturdier than a flat baseplate, it can hold apart skin folds to expose the stoma. Sometimes the use of convexity can mean other accessories such as paste or seals that were used to achieve a seal are no longer needed.

What about a belt?

All convex pouches are manufactured with belt loops. This is to give you the option of using a belt to increase the security. The belts are elastic with a size adjuster and, as they pull the pouch more firmly in position, they have the effect of increasing the firmness of the convexity. They should not be made too tight and should be





Pictures courtesy of Pelican Healthcare Ltd

comfortable, with two fingers easily able to be inserted under them.

What can go wrong?

There is a risk, when using a convex pouch, of causing bruising around the stoma by the pressure on the area. This risk will increase with the use of a belt, and should be monitored by regular checks by the stoma care nurse. If bruising occurs, loosen the belt and ask the advice of your stoma nurse.

It is important to ensure when attaching the belt that the hooks are facing outwards, away from the body. They can cause bruising or trauma when pushing against the abdominal skin. Similarly, the belt can cause sore chafed skin over bony prominences such as the hips and spine on people who are slim or underweight, so it might need to be loosened or some soft material tucked under the belt in these areas.

Convexity generally should not be used on newly formed stomas as the pressure can delay healing and cause trauma to the mucocutaneous junction (the suture line where the bowel is attached to the abdominal skin). Occasionally, when there are real problems with leakage in the early post-operative days, a gentle convexity can be used, but only with close monitoring by the stoma care nurse.

Which convexity should I use?

This obviously depends on why it is needed. Sometimes a gentle convexity is all that is needed whereas in cases of severe retraction, a deeper, stronger convexity will be required. The choice should be guided by your stoma care nurse, with perhaps several types being sampled before making a decision. The belt also requires some trial and error. Some people choose to only wear it at times when increased

security is needed such as over night or when going out and then take it off when relaxing at home. For others, the belt is an essential part of using the convexity or you might find it is not necessary.

Convexity is often offered with different sizes of 'plateau' or the raised area. It is generally felt that it works more effectively when the convexity is quite snug to the stoma. I.e. using a convex pouch with a large plateau on a small stoma wouldn't be very effective as the pressure is further away from where it is needed.

In conclusion:

A convex baseplate certainly is very effective for many who have experienced problems with leakage for a variety of reasons. It should, however, always be introduced and regularly monitored by a stoma care nurse.

Products designed to promote healthy skin and make living with a stoma easier.



For all the help you need
0800 458 7605
www.opus-healthcare.co.uk

Readers' writes

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

Dear CA

I was operated on in May 2010 for a large colorectal cancer. Thanks to the wonderful efforts of the Southampton Cancer team I have, at the venerable age of 83, made a good recovery, to the extent that I managed to visit a son in Singapore in November last.

I am writing to you to point out the fact, of which I am sure you are aware: Bowel Cancer test kits are not sent out to people over the age of 70. In my case, I was fortunately proactive, and personally applied for the kit. The results were abnormal, and the rest is history. I think it is important for you, through your pages, to advise your readers, who have been through the trauma, to spread the word among family and older friends and acquaintances to take this vital free test.

I have taken part, with my specialist, Alex Mirnezami, in making a short video on Cancer Research UK and YouTube, highlighting his research into the problem of returning rectum tumours in some cases, plus the urgent need for early recognition of Colon Cancer.

For more information
www.cancerscreening.nhs.uk/bowel/

Yours, in grateful thanks for a splendid magazine.
M.L. (Mr)

Dear Tidings

Being a new colostomate, I would just like to understand what is the correct disposal procedure for normal closed bags? In public toilets, do females use the sanitary towel bins? Normal paper disposal bins don't seem appropriate to me.

With normal household disposal, is it better to keep bags together or just "dump" as appropriate? Is there anything on the market to use in bins to mask odour, particularly for the summer?

Also when in hotels, in the UK or abroad, where there is only a normal disposal bin in the bathroom, is this appropriate to use or should you make the hotel aware? That doesn't add to one's enjoyment, but really just want to know the correct thing to do, particularly from a hygiene point of view? I realise I can ask my stoma nurse too but wondered what your advice is.

Thanks in advance.
R.T. (Mrs)

Rosemary Replies: Yes, used stoma bags may be disposed of in sanitary bins in public toilets and in pedal bins in the bathroom at a hotel. Some people prefer to empty the bag before sealing it inside a disposal bag. However, if you find it impractical or unacceptable to empty the bag make sure you wrap it up very well. There is no need to make the hotel aware as staff should empty these bins daily and handle and dispose of the contents hygienically as other guests discard babies' nappies and sanitary products in this way. There are several dustbin deodorizers on the market e.g. Neutradol, Bin Buddy and Freshbin. These powders, which you sprinkle inside the bin, are available at supermarkets or on-line.

Dear Friends

Be assured that I read Tidings from cover to cover and I can relate well to the contributors' experiences.

I am a pensioner who experienced a bowel resection in 1985 and colostomy in 1997. I've had some serious problems and obstructions over the years. However, on the whole I feel better now. I have an inverted stoma which has caused problems and embarrassment for a long time. Recently I was introduced to Cohesive Slims, seals which are placed on the skin around the stoma, before fitting the bag. Now with the Slims I keep my flange on for four to five days – What a blessing!!

I have a lovely wife who has sympathy and cares for me. She has really been good to me over the years and we both look forward to our golden wedding later this year. The world has changed over the last five decades. Again thanks for Tidings and good wishes for our Association.

Yours
W.D.W. (Mr)

Dear Madam

I would like to convey my thanks to the association for sending me the Tidings magazine. My friend contacted the association in 2009 and explained I was due to have surgery in March this year and you kindly sent a load of information. Unfortunately I was unable to look at this until after my operation in May.

Thank goodness I did as the information contained in the magazines and the free samples that have come with them have been

Readers' writes

marvellous. On reading some of the adverts my friend started calling the suppliers for various samples and at long last I am on the way to sorting out exactly what are the correct items for me. You are never told that there are other products you can try instead of those given to you following your operation and you seem to go through a long period where soreness sets in and you struggle to sort yourself out. So my four copies of Tidings are really well thumbed!

One of the articles which proved to be of immense help was by Virginia Ironside in the Spring 2010 issue where she mentioned the Trio Diamond sachets. My friend immediately got in touch with Fittleworths (my supplier) and they sent a load of sachets which have been very successful at night. Now I can sleep for over four hours before I need to get up. What bliss as I had been struggling to get an hour's sleep at a time.

Thank you so much for all your help this year.

Yours sincerely
A.A.P. (Mrs)

Dear Editor

I have been irrigating since 1987, three months after my operation. This has worked exceptionally well over the years. I irrigate on alternate days and I use tap water wherever I am. My husband and I have travelled abroad extensively, including cruise ships and river boats. It was only when in Syria staying in the back streets in Damascus, did I think the tap water might have been suspect! I did get an upset tum!! We enjoy long distance walking, such as Wainwright's Coast to Coast walking West to East, Offa's Dyke walking South to North and many others both in this country and abroad. The only thing I have stipulated when travelling is to have en-suite facilities so that irrigating has never been difficult.

The only ghastly situation, in which I have found myself, was in Cairo when we visited the pyramids. At

that time, while I was still working, I used the Conceal Plug (excellent) but in my rush to get out to see the pyramids I hadn't really completed my irrigation properly. While on the coach I was suddenly in a horrendous mess! Fortunately we were cruising with Swan Hellenic and the Cruise Manager whisked me into an hotel where the others were having coffee and ordered a bedroom for me - so I was able to shower and wash my clothes. No mishaps since then thank goodness!!

On a funnier note, we were in Prague on the tram and I was hemmed in by four youths. I didn't think anything of this until I discovered my bumbag had been opened and they had taken a make-up pouch, which was actually full of my (clean) spare colostomy bags etc. We roared with laughter, thinking of these youths opening up what they thought to be a wallet full of money!

I'm hoping that your readers might help me - I am intrigued with the irrigation pump and wonder if it might be of benefit to me. I hesitate buying this because of the cost of the pump. I would like to know if it is bulky to travel with, as these days we limit ourselves to one small case each plus hand luggage. I would also like to hear of the advantage this pump has over the water bag. I find it easy enough to control the speed of the water flow. I rarely have difficulty hooking it onto something, although my husband has needed to hold the bag for me on rare occasions.

Yours faithfully,
M.K.H. (Mrs)

Rosemary Replies: CA arranged for a volunteer who irrigates using the Braun Irrimatic pump to telephone this lady and answer her questions. The pump measures 7inches by 6inches and is 7inches high and it weighs 2lbs 3oz so it can easily be carried in hand luggage. It is not available on prescription and costs £260.64 +VAT.

Dear CA

Thank you for directing me to the Gay Ostomates website. I wish I had found this site before my operation. Neither the colorectal nurses nor the consultant surgeon could give me any advice (as a gay man) on how I would cope after the surgery.

I had an operation in July 2005 to remove a tumour followed by chemotherapy. Now it has been discovered that the cancer has returned lower down in the pelvis. I was told that there was a strong possibility that my rectum, prostate and bladder would be removed and I wanted to contact other men who had gone through a similar situation (i.e. living with two pouches). It did not matter whether they were gay or not. I could not find anyone.

The Gay Ostomates site is brilliant. The information is clear and to the point. I would recommend it to anyone who is facing an operation which means a life with a pouch. You feel that you are not alone and there is support outside the medical fraternity. I recommend this site as a source of information and stress that the gay element is very low key. It is not a dating agency just a very friendly site. My partner has found it as useful as myself. For more information visit www.gayostomates.org/

Best wishes
B

Dear Editor

I have much enjoyed the winter edition of Tidings as I always do.

I was particularly interested in the new series, beginning with the article about Welland's Free Style Vie flushable pouch. It came on the market a few months after I acquired my colostomy (in 1995). It was then called Impact, and made such a difference, not only re flushing, but also because my original pouch did not adhere very well to my skin.

I have attended a number of meetings with the clinical research team in Crawley and have trialled

Readers' writes

quite a few "prototype" pouches. I hope that article really will spread the word, as I am certain it could improve the lives of many colostomates, who are not yet using a flushable pouch.

Yours sincerely
M.L. (Mrs)

Dear Tidings

Thank you so much for my regular deliveries of your magazine which I find very informative.

Like some of your readers in the winter issue I had surgery - an abdomino-perineal resection - to remove a tumour at my anus. I opted for a permanent stoma as my surgeon said that doing reconstructural surgery gave me a higher risk of the cancer coming back.

My story is probably one you have already heard before. At fifty-two I put my weight gain and worsening constipation (which I had suffered for most of my adult life) down to the menopause and only went to see my GP on the insistence of my lovely husband and then it was only to "shut him up". After tests the cancer was diagnosed in January 2008 with surgery in March.

My stoma decided not to work for five days but fortunately, just before the surgeons were considering taking me back to theatre, it finally "performed". The only other problem I suffered was an awful discharge from the perineal wound and because I'd had radiotherapy before surgery it didn't heal up as it should have done. The wound had to be packed for the next four months. The nurses were all very understanding and made what was a difficult time more bearable.

I'm now coming up to my third anniversary since the surgery. I'm fit and well despite a little "glitch" with skin cancer - a basal cell carcinoma removed in June 2010. I'm able to do 99% of the things I used to do.

I do have a problem now with my weight so your article by Sophie Medlin is very helpful. Thanks again for a great magazine.

Yours sincerely
S.S. (Mrs)

Dear Editor

We all remember the daunting time when we first had our colostomy. My lucky break was living near Reading. I was walking along the road and noticed the sign Colostomy Association. I rang the bell went in and found a whole new world of support including Tidings.

I went to see my GP today (nothing serious) and asked permission to put Tidings in with the magazines in the waiting room. I also told her about CA and how much I wished I had known about them when I first had my colostomy. I said how much CA had changed my life and wondered if she could pass on the message to anyone who might be interested. She immediately agreed and said she would also e-mail the other partners in the practice.

Would it be a good idea for all of us to approach our GPs and ask them to spread the word? Maybe we could also put Tidings in the waiting room at the chemotherapy department.

Best Regards
J

Rosemary Replies: What a good idea. Do any other readers put Tidings in hospital or surgery waiting rooms? Please write in and let us know.

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

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

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

associate-editor@colostomyassociation.org.uk
or write to:
Associate Editor
Colostomy Association
2 London Court,
East Street,
Reading RG1 4QL

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



Yours
Rosemary Brierley
Associate Editor



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.

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Dear Nurse

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

Q: *My husband Richard is a member of your association and has been since he had bowel cancer in 2007. Over the last 6 months he has been leaking a smelly liquid from his back passage and today announced that he is loosing blood so the incontinence pants he has used at night will now be worn in the day time. He is very calm about this and I am very worried. He suggests he will go to the doctor in the week. I would be interested to know what I am likely to need to know for the future, if you have any past experience with other patients that might help. I am sorry that I do not know his login details, but I am of the opinion that he is not keen to find out although is sensible enough to realise things are not going to get better by themselves.*

A: It is not unusual to pass mucous from the back passage following stoma formation. However if the discharge is offensive or contains blood I would suggest a review by the GP. It may be a simple problem such as proctitis or inflammation but it does need investigating to ensure the correct treatment is given, especially as the output has changed and if pads are needing to be worn then it suggests there is a control issue and a larger amount.

Q: *My 84 year old mother has a loop ileostomy, following bowel cancer surgery three months ago. Unfortunately very shortly after the surgery she developed a hernia at the stoma site. The consultant wanted to do an immediate reversal due to the hernia, but the bowel was not sufficiently healed. She is now due to have the reversal done on 13th*



Julie Rust became Tidings Nurse in December 2004. She has answered readers' letters and e-mails in all twenty-five issues which have been published since then. We look forward to many more years of publishing her very sound advice.

Your medical questions about stoma care management are always welcome and important to us.

Questions received by the Editor or CA are passed to Julie Rust RGN. Dip, N. MSc. CNS Stoma Care to review and answer. Answers are published in the next issue of Tidings.

December. In talking to her consultant I have discovered that most of her rectum was removed during the surgery. In that case is the reversal a good idea? We were told that he could not just repair the hernia; consequently he wants to do the reversal and the hernia simultaneously. What do you anticipate her quality of life will be following the surgery? Will she have enough bowel control? Or will she be tied to the house for evermore? My mother was and indeed still is a very active woman and I am concerned

that this reversal could significantly reduce her quality of life. Are there any exercises she can do or medication she can perhaps take to reduce the effects of this procedure perhaps?

A: I do hope that if your mother has already undergone the surgery for a reversal of her stoma that everything went well. Bowel control following reversal can be very erratic for several months post reversal but usually does settle with time. I am unaware as to how much bowel was removed and obviously the shorter the large bowel the looser the output will be. The surgeon would not usually suggest a reversal if it were felt there would be a significant control issue afterwards. It is very common to have a short segment of the lower bowel removed and the join protected with a loop stoma for a period of time post-operatively. The success rate for reversal and control of the bowel function after this is usually good but may take some time to settle.

Q: *I wonder if you can help with a little problem, since we could not find a related article on the website. My husband is a colostomist and although the flange and colostomy bag fit well around the stoma, his bag is not releasing gases and gets blown up. He tried to punch a little hole in the filter to allow the gas to pass but that is causing leaks which naturally stain his underwear. Is there something he can do to work his way around this situation? Any suggestions are welcome.*

A: The amount of wind passed is often related to diet and keeping a food diary for a short period of time is often useful at identifying the culprits. Once these are identified then a decision can be made to either discontinue eating the particular food or to be prepared to manage the wind problem. Some people find the use of peppermint (tea, mints or cordial), fennel (vegetable, mints or tea) or charcoal (tablets or biscuits) useful in helping to reduce the

amount of wind passed. These are available from many health food stores. Alternatively trying a different product with a different filter system may be worth trying.

Q: *I have had my colostomy for 19 years without encountering any great problems but recently I have developed what appears to be a nervous rash on my abdomen to the left of my colostomy but just outside the adhesive ring of my colobag. My GP has prescribed TIMODINE Cream, which I apply twice a day that successfully keeps it subdued. However if I happen to miss a treatment it quickly flares up, becomes inflamed, very tender and sore.*

Have you encountered such a condition and are you able to suggest how it might be eliminated? I would greatly like to be relieved of this problem and would appreciate your help.

A: This is a difficult one, as I have obviously not seen this rash so it is difficult to assess the possible cause. The fact that it is away from the adhesive flange of the pouch makes an allergy unlikely. It may be that regular use with the prescribed Timodine Cream for a short period of time will clear the rash up completely. However if it does not improve things over the time the GP has prescribed it for it may be worth asking for a dermatology review. It may be that the rash is nothing to do with the stoma or the products and is a dermatological problem which can be investigated by a Dermatologist and then specific treatment prescribed.

Q: *I had a colostomy for the treatment of rectal cancer nearly three years ago. I have been well since and have had no problems with managing my stoma, but I do have severe anal itching, which I find very troublesome.*

I mentioned it to my consultant, but he did not seem to think it was of great significance. He advised against anti-itch preparations, but thought a barrier cream such as Sudocrem might help. I have tried this but it had no effect. The only thing that helps slightly is Vaseline. I hesitate to raise the matter, as it seems such a small problem compared to the troubles other readers have. I do know how lucky I am and I count my blessings every day.

A: This can be a very irritating problem and is difficult to manage. There are several creams and ointments on the market such as Anusol, which can help. Alternatively there are many barrier creams, sudocrem being one, which are available as nappy rash treatments. If you speak to your stoma care nurse there are also many creams available on prescription such as Comfeel or Ostoguard and she may be able to get some samples for you to try.

Q: *I am inquiring about some problems with discharges from time to time from the rectum. I have had a colostomy for eleven years. I get a creamy yellowish pasty discharge that usually carries on for a few days. It doesn't smell or hurt but it is uncomfortable and I am worried if something is causing this condition to occur.*

A: This sounds like a mucous discharge from the rectum and is very common. Some people never get it, others get it occasionally and a few suffer with it on a regular basis. If you have the sensation that you need to empty your back passage then sitting on the toilet and gently pushing (do not strain) can help to empty the rectal stump. Alternatively if it is okay with the surgeon a Glycerine Suppository gently inserted into the rectum can help to empty the mucous out.

Q: *I have a temporary colostomy due to IBS, having the colostomy has been like having a holiday and I am now concerned that if or when I am reversed I will continue to have the IBS as bad as before and don't know if I can face that. Is this likely?*

A: I would suggest a good talk with your consultant regarding this. No one can insist you have a reversal but you must be aware of all the options for both keeping the colostomy and reversing it and what the outcomes could be. Maybe speak to your surgeon and discuss things in detail with your Stoma Care Nurse, both of whom will be more aware of your individual situation and can advise accordingly.

What kind of stoma do you have?

When food leaves the stomach it enters the small intestine, a long coiled tube about twenty feet long. The last part of the small intestine is called the ileum. If the ileum is brought out through the abdomen to form a stoma (ostomy), this is called an **ileostomy**.

Five facts about an ileostomy

- The name comes from combining the words ileum and ostomy.
- It allows faeces to leave the body without passing through the large intestine (colon).
- It is usually on the right hand side.
- The output tends to be fairly liquid – the consistency of porridge or thick soup.
- A drainable bag is used and emptied four or five times a day.

Normally digested food passes from the small intestine directly into the large intestine or colon. If the colon is brought out through the abdomen to form a stoma (ostomy) this is called a **colostomy**.

Five facts about a colostomy

- The name comes from combining the words colon and ostomy.
- It allows faeces to leave the body without passing through the anus.
- It is usually on the left hand side.
- The output tends to be formed and firm.
- A closed bag is used and changed about twice a day.

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

Editors Comment

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

If so write in and tell us:

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

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

Hints and tips for new ostomates

When changing your colostomy bag

Use a peg to ensure your clothes are free of the stoma area. Try joining two pegs with a piece of cord long enough to hang round your neck and clip a peg on each side to secure and support your clothing in a more balanced way.

Standing upright while applying your clean bag will help to eliminate folds and creases and ensure a good seal on flattened skin.

It is not unusual for slight bleeding to occur where your bowel is stitched to the skin, so handle your stoma with care. However, if there is blood coming out from inside the stoma it is important to seek medical advice.

Try putting your new, clean flange/bag in a warm place e.g. on top of a radiator or under your arm for a few minutes to warm the adhesive which will help it to stick.

Some people find it easier to position their flange correctly if they stand in front of a mirror.

Stomas can change shape and size, especially in the first few months, so check weekly for any changes.

Many stomas are not round. Make sure that the flange fits as snugly as possible. If the hole is too big this can lead to sore skin. If it is too small the adhesive will be up against the side of the stoma and won't stick, allowing motion to collect behind the flange and cause leaks.

When measuring your stoma, use the backing paper of the flange as a pattern. Place it over your stoma then look in a mirror to check that it is the right size.

Gentlemen who have hair on the abdomen can shave away the hair around the stoma. To protect the stoma whilst shaving pop a cardboard tube from a used toilet roll over the stoma or cover it with the lid of an aerosol can.

When showering with a colostomy bag still on, remember to cover the filter so it doesn't get wet and stop working. If you have problems drying the outside of the bag try using a hairdryer, but switch it to the lowest setting so there is no risk of melting the plastic or damaging the stoma.

If you have sensitive skin, before using a new type of appliance always patch test it on a small area - the other side of your tummy is best - in case of a reaction to the adhesive.

Changing your bag away from home

Don't forget your spare kit (stoma bag, wipes, scissors, disposal bags etc.) when you go out...and remember to renew it on a regular basis.

Many colostomates find it easier to change their bag in a wheelchair-accessible toilet where there is a wash basin and a bin for disposal on hand. See back page for details of how to obtain a RADAR key which opens locked toilets all around the UK.

When you know you will have to use public conveniences and there is no running water, take with you a very small "Body Shop" style spray bottle filled with water. Bacterial hand wash that does not require water is also useful. Some stoma appliance companies produce sachets of cleansing gel which are available on prescription.

Try flushing the toilet before you use it just to make sure that it is actually working. There is nothing worse than finding out too late that it doesn't flush at all!

Clothing

You will usually be able to wear the same clothes as you did before surgery.

Ladies who find wearing normal tights uncomfortable could try maternity ones. "Hold up" stockings are another option or "knee highs" if you are wearing a long skirt.

Wearing skimpy briefs which finish below the stoma or high-waisted pants that rest above the bag will prevent the waistband pressing on the stoma which may affect its functioning or lead to leakage.

Several companies make specialist underwear with an inside pocket which supports the stoma bag and keeps it away from the skin.

If the stoma is on the waistline gentleman may find using an elasticated belt or braces preferable to wearing a rigid belt.

High-waisted trousers may be more comfortable. Details of manufacturers and suppliers can be obtained from head office.

Patterned swimwear will camouflage any bulges.

Stoma bag covers, which will help to prevent your bag sticking to your skin in

the heat, are available from some manufacturers.

Always wear a support garment when lifting heavy objects. Consult your stoma care nurse for advice on which type is most suitable for you.

Dealing with: Odour

Most stoma appliances have a filter which incorporates a deodorizer, so odour shouldn't be a problem. However, if you are not happy with the filter on the bag you are currently using there are other bags made by different manufacturers that you could try.

Several manufacturers and suppliers of stoma care appliances produce drops or granules designed to neutralize any odour. These can be introduced into a clean bag before you put it on.

Odour could mean leakage or the filter may have come into contact with the contents of the bag making the deodorizer ineffective. If so change your appliance as soon as possible.

Some ostomates find that drinking tomato juice or buttermilk or eating natural yoghurt or parsley helps to control odour. Others take peppermint capsules.

Wind

Drinking peppermint tea or peppermint oil in hot water can help to reduce wind.

Eating fennel or drinking fennel tea is another remedy.

Pancaking

This is when the output collects around the stoma and sometimes squeezes between the flange and the skin instead of going into the bag. One of the reasons this happens is because there isn't enough air in the bag and so the output doesn't take a downwards turn.

Lubricating your bags with baby oil or one of the many products available from the various supply companies will help the motion to fall to the bottom of the bag. Squirt a little oil or gel into your bag and give it a good rub around before you stick it on. Take care not to get any on the adhesive as this can reduce the effectiveness of the seal.

Covering the filter with one of the sticky patches that are supplied in each box of stoma bags will prevent a vacuum forming inside the bag.

Leakage

Ask your stoma nurse about rings and washers which can help to give a really good seal around the stoma.

Fifty years with a stoma...

John takes us back to a time when stoma care was in its infancy and explains his journey of some fifty years of 'living with a stoma'.

In 1956 on my four day flight to an RAF station in Penang Malaya I succumbed to the runs. Not an unusual experience for national servicemen going out east, but mine persisted and I found myself in and out of sickbay and hospitals for the next six months. After treating me for dysentery I was finally diagnosed with ulcerative colitis. I was flown back home to England and treated at RAF Halton on drugs and a non-roughage diet. Hence I flinch at the thought of jelly and custard.

After a further six months in RAF Halton, I was invalided out of the Air Force and learned the whereabouts of every public toilet within the Wood Green area, where I lived with my parents. I was very near to dehydration a lot of the time. When I look back I am amazed at how I managed to go to work and be active with our church youth club. How resilient we are when we are young.

Finally my condition and my poor diet got the better of me and I landed up in St. Marks Hospital in London. I was privileged to be under the care of Mr Avery Jones. He changed my diet and I was built up ready for my ileostomy operation. On Nov 5th 1959 I stood there shaved in the nether regions watching fireworks out of the hospital window. I was jubilant knowing that the next morning I was going to have a new start. Hurrah! To be without stomach cramps and the runs and to eat what I wanted. It couldn't happen quickly enough. Looking back I have to thank the dedicated staff at St. Marks for without their pioneering expertise I would not be alive now.

And so it worked out as they said. I had youth on my side and I had friends to catch up with. Of course there was the small matter of getting used to the Salts rubber bags. These relied on the elasticity of the bag opening as it was pulled over the grooved rubber flange. Woe betide you if too much weight filled the bag or you caught it inadvertently when fooling around. A double-sided Chiron plaster stuck the flange on to my stomach with one-inch wide zinc oxide plaster strapping to give the final touches. A wedge of cotton wool acted as leak protector between my



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stoma and the flange and had to be changed every day. The bag was also replaced in rotation daily by another which had been washed out and left in an enamel bucket to soak in bleach to kill the odour. The bag was emptied through a round hole at the bottom which had a screw in plug. My source of supply was Boots the Chemists.

I was flying solo. At that time there was very little happening in the way of specialist nursing teams who now do such a wonderful job. The fact that I was young and didn't want to be seen as different to my friends discouraged any thought of ostomy groups. In hindsight I can now see that their support and encouragement is a must for many. In 1964 I married my lovely wife and moved from London to Hampshire where I first became aware of some of the changes that had taken place in the types of appliances. But I doggedly pushed on with my rubber bags. I was loathe to change. Then it happened. I was told they had stopped doing the flange I was using. How thoughtless, how could they do that to me!

It was a blessing in disguise though as I was forced to take the plunge and start using a more modern appliance.

Can I really dive into a swimming pool without losing my bag? Yes! Wonder of wonders! Do I have to change it every day? No! How grateful we must be.

Although slight of build I have always loved DIY from replacing ceilings to putting in central heating and two years ago putting in a new shower unit. Apart from overdoing it a few times I have remained fairly fit with my stoma behaving well. I am seventy-five in August and still happily married with children and grandchildren. I am also known to fall asleep after lunch. I still clean the bungalow cladding and crawl under the floors. I must admit that I do it much slower now and get a lot of grumbling from my muscles afterwards. I also go easier on lifting and wear stoma support wear. My stoma is not too intrusive and I keep Ili happy with a few exercises most days. Ili and I have been travelling together now for fifty-one years and he's been a very good companion to me as he very rarely grumbles out of turn.

John Belleguelle

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'The Group provides non-medical support and advice to ostomates, their families and/or friends during all stages of ostomy surgery - prior to surgery, during hospital stays and aftercare.'

Michael Slater writes about... the **Wessex Stoma Support Group** based in Salisbury



Members of the Wessex Stoma Support Group

The Wessex Stoma Support Group was borne from the idea that there was a real need for a local support group that would encapsulate all ostomates; be they colostomates, urostomates or ileostomates because, prior to 2006, bladders and bowels did not generally mix!

So, early in 2006 the inaugural meeting of the Wessex Stoma Support Group took place in the Chalke Valley at Fifield Bavant. It was agreed that everything possible would be done to help all ostomates. Our numbers now total 35 members consisting of all three types of ostomate and we want to continue to expand.

Our members come from as far afield as Lymington in Hampshire and Swindon in North Wiltshire. We are just approaching our fifth year and once again looking forward to our annual invite to the delightful Dairy House at Fifield Bavant overlooking the picturesque Chalke Valley.

We are represented at Salisbury District Hospital's Stoma Clinic Open Days, which give anyone who has a stoma and would like to meet other ostomates a chance to talk to us and enjoy an afternoon out.

In 2007, it was decided at our A.G.M. that it was necessary to introduce a Membership Fee and this would be £5 to be paid annually and be reviewed at our A.G.M. Since then it has remained at £5 and will be proposed to remain the same until at least 2011. Full membership is open to ostomates, their

families and/or friends and meetings are held currently at the Bob Blandford Memorial Hall, Wilton (Wilton Scout Hut).

It is the aim of the Group to give non-medical support and advice to ostomates and their families during all stages of ostomy surgery: prior to surgery, during hospital stays and also aftercare. We have trained advisors to provide non-medical support.

We hold regular meetings approximately four times a year, where we often invite guest speakers and suppliers to do talks and displays. This is followed by free refreshments and cakes - many home made by the ladies in the Group and ably served by Ruby and Jean. All this comes with a pleasant chat and informal atmosphere. Members also enjoy our social side: Barbecue, Christmas Lunch, Afternoon teas and much more.



Members enjoying the summer BBQ in 2010

We have regular fundraising events including car boot sales but our main fundraising is done through table sales at various venues. We offer free transport to Hospital for stays, for visits to clinics and for visiting relatives if they have no other means of transport.

There is a strict code of confidentiality for all our members. We also produce our own quarterly newsletter with regular input from Salisbury District Hospital stoma nurses.

The Group has a fully elected Committee, which meets on a regular basis to discuss policy and any other matters raised by the members during the full meetings.



Committee meetings are held regularly

It is the Group's aim to work closely with Salisbury District Hospital for the benefit of our members or any ostomates who may show interest in joining the Group.

Our next full meeting is on Saturday August 20th at 2pm, held at the Bob Blandford Memorial Hall (Wilton Scout Hut).

If you require further information about our forthcoming meetings or any other information about the Wessex Stoma Support Group...

simply contact the Secretary on:
01722 741233

or write to:
Mr M. A. Slater
The Secretary
Wessex Stoma Support Group
55 Wishford Road
Wilton
Salisbury
SP2 0JG

or email:
wessexstoma@yahoo.co.uk

or visit:
www.wessex-stoma.co.uk

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

Stoma support groups in your region...

Information about Support groups is regularly revised. If you know of a **support group** not mentioned in our listings please get in touch...

e-mail: editor@colostomyassociation.org.uk



Scotland

Midlothian:

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

Glasgow:

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 311266 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
Behind You (Calderdale & Huddersfield Bowel Cancer Support Group)
Contact: Michelle Speight 01484 355062
CROPS (Colo-rectal ostomy & internal pouch support)
Contact: Gloria 0114 2879503
Dewsbury & District Ostomy
Contact: Janet/Eileen 0844 8118110
Rotherham Ostomates Caring Support
Contact: 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 Pete Rennard 01482 793966

Isle of Man:

Stoma Support Group
Contact: Carole Cringle 01624 650212

England - Central

Buckinghamshire:

Milton Keynes Stoma Association
Contact: Bruce Pollard 01908 582563

Leicestershire:

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

Nottinghamshire:

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



SUPPORT GARMENTS

All of the garments illustrated are available on prescription from your family doctor. Relax and look through the brochure in the comfort of your own home or together with your Stoma Care Nurse who will be pleased to help you make the correct choice. Think about your own needs before choosing a garment. It may be that you will need abdominal support all of the time if you have a hernia. You may like different styles for different occasions or you may just like one particular style to wear when going out and about.

Many of our clients prefer to wear the garments as they are but we can alter any of our garments to make a **hole over the stoma if you prefer.**

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We will make every effort to ensure a good fit within the size range available although sometimes this takes a little extra time.

For a full brochure, help at any time or if you have any questions please call us on our

HELP LINE 0845 757 3023

we will be pleased to assist you in any way we can.

You may view ALL of our garments on the Hi Line web site www.hiline.ltd.uk



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**Bedfordshire:**

Saturday Social Club
 Contact: Karen Richards
 01234 792278

Cambridgeshire:

Ostomistics
 Contact: Heather Connor 01733
 768332 Mob: 07757167422

Essex:

Connect
 Contact: Lin Hart 01279505273
 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:

Connect
 Contact: Lin Hart 01279505273
 Colonise
 Contact: Gill 01727 851556

Lincolnshire:

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

Norfolk:

Ostomy Friendship & Support Group
 Contact: 01553 691370
 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

Isle of Wight:

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

Kent:

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

London:

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

Middlesex:

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

Oxfordshire:

Oxfordshire Ostomy Fellowship
 Contact: Pat Longworth 01235 524163

Surrey:

Epsom 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 Newry
 Contact: Bernie Trainor
 028 3883500 Ext 2222
 Mater Hospital Belfast
 Contact: Karen Boyd
 028 90741211 Ext 2329
 Southern Trust
 Contact: Mary Jo/Bernie
 028 38612721

Eire

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

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

List of forthcoming Open Days:-

Date: 4th May 2011
Venue: Thornton Manor, Wirral
Time: 9.45am-1pm
Organiser: Hollister

Date: 5th May 2011
Venue: National Glass Centre, Sunderland
Time: 10am – 2pm
Organiser: Salts Healthcare

Date: 6th May 2011
Venue: Lord Hill Hotel, Shrewsbury
Time: 12noon – 3pm
Organiser: Shrewsbury and Telford Hospital

Date: 10th May 2011
Venue: Park Hotel, Kilmarnock
Time: 11am-1pm
Organiser: Hollister and Dansac

Date: 11th May 2011
Venue: Savoy Park Hotel, Ayr
Time: 10am-12noon
Organiser: Hollister and Dansac

Date: 11th May 2011
Venue: Carlton Park Hotel, Rotherham
Time: 10.30am – 2.30pm
Organiser: Rotherham Hospital

Date: 12th May 2011
Venue: The Eden Project, Truro
Time: 9.45am-1pm
Organiser: Hollister

Date: 17th May 2011
Venue: West Midland Safari Park, Worcester
Time: 9.45am-1pm
Organiser: Hollister

Date: 18th May 2011
Venue: Belfast Castle, Belfast
Time: 9.45am-1pm
Organiser: Hollister

Date: 1st June 2011
Venue: Palm Court Hotel, Aberdeen
Time: 10am-12noon
Organiser: Hollister and Dansac

Date: 7th June 2011
Venue: Heath House, Staffordshire
Time: 9.45 – 1pm
Organiser: Hollister

Date: 9th June 2011
Venue: Hever Castle Kent
Time: 9.45am-1pm
Organiser: Hollister

Date: 10th June 2011
Venue: Apex Hotel, Edinburgh
Time: 11am – 3pm
Organiser: Salts Healthcare

Date: 15th June 2011
Venue: North West Castle Hotel, Stranraer
Time: 10am-12noon
Organiser: Hollister and Dansac

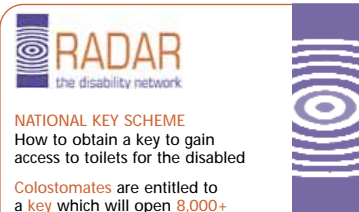
Date: 16th June 2011
Venue: Station Hotel, Dumfries
Time: 10am-12noon
Organiser: Hollister and Dansac

Date: 22nd June 2011
Venue: King's Hall and Winter Gardens, Ilkley
Time: 10am – 2pm
Organiser: Salts Healthcare

Date: 24th June 2011
Venue: Royal Highland Hotel, Inverness
Time: 11am – 2pm
Organiser: Salts Healthcare

Helpful Ostomy Support Groups & Organisations...

- IA The Ileostomy and Internal Pouch Support Group
 Freephone: 0800 0184 724
www.iasupport.org
- UA Urostomy Association
 Tel: 01889 563191
www.urostomyassociation.org.uk
- IOA International Ostomy Association
www.ostomyinternational.org
- 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



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

Don't forget...World Ostomy Day - Saturday 6th October 2012

If you have any fundraising ideas or suggestions on how CA can celebrate **World Ostomy Day**...contact the Editor via CA head office: 0118 939 1537 or Email: editor@colostomyassociation.org.uk - thank you!

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..... Post Code

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 for more information and a brochure:
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 Mobile: 07968 370498

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