

Spring 2009 | Issue 13

Tidings

colostomy association

Dedicated to Colostomates their Families and their Carers

inside...

Open Door
driving spirit
Claire BohrCNS
Bristol Royal Hospital
for Children

Aspects of medical treatment
Consultant writes
about...resiting

Travel
Cruising
on the high seas

plus...
all our
regular features

- **Readers' stories**
- **Dear Nurse**
- **Your letters**

Happy Easter to ALL our readers from the Colostomy Association...

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welcome to SPRING



The Colostomy Association goes to the Palace...

Maureen Kelly-Smith of SecuriCare was so impressed with the work being done by the CA that she put forward the Association's name for a prestigious occasion.

Sue Hatton and Ernie Hulme were invited to an evening reception given by the Queen at Buckingham Palace for those working in healthcare in the United Kingdom.

Sue explains...

Ernie and I arrived at 5.30pm and joined a queue of amazing healthcare professionals - from surgeons to clerical assistants to paramedics. After entering the Palace, everyone was directed to the Blue Gallery, the Throne room. Drinks and delicious canapes were offered and after half an hour, Ernie and I were asked to move forward and hand the yellow cards we were clutching to an equerry.

"Suddenly my name was announced and the Queen was standing in front of me, somehow I dropped a curtsey and said something like 'Thank you so much your Majesty', before shaking her hand and gazing into those startlingly bright eyes and smiling face".

It was extraordinary, very moving and very emotional. Afterwards Ernie and I reflected on the great honour that had been bestowed on the Association and on us, so thank you to Maureen and the CA for choosing us to represent you!

It's official spring is here...if like me you are a keen walker you must have noticed the subtle changes steadily taking hold in the countryside - and it's about time too.

This winter has been a long haul and seems to have gone on forever made worse by the ongoing commentary in the media, highlighting effects of the credit crunch. There must be some good news they could comment on!

My highlight this winter without doubt was reading the numerous emails and letters sent in by YOU the readers. I would like to take this opportunity to thank each and every one of you for your feedback, queries, advice and innovative suggestions - you have definitely taken up the challenge. Unfortunately, I am not able to publish all your letters but have included as many as possible within Readers' writes.

The information contained in your letters helps to inform and reassure so many Tidings readers. The added benefit is that the editorial team is able to plan ideas for articles for future issues of Tidings that are relevant to you. So, keep them coming!

I have introduced a prize for the best readers' letter; the lucky winner will receive a £20.00 gift card from M&S.

In this issue of Tidings we have a mix of articles as well as all the usual favourites. Open Door has been down to Bristol Royal Hospital for Children to interview award winning paediatric nurse Claire Bohr, Claire tells us about her ground-breaking work teaching children to use rectal irrigation. The Pathway series features a story by Sonia Woolven about her surgery in the USA and irrigation. Tidings is introducing a regular page on irrigation - so why not write in and tell us about your experiences, technique, hints and tips or queries and we will include them in future issues.

With warmer weather on the horizon, holidays come to mind. A number of you have been in touch to say that your preferred holiday takes the form of cruising. We take a look at planning a cruise holiday and give those of you who might like to take a cruise a few tips and a taste of what others have enjoyed. Colostomate Rosemary Brierley shares her cruise experience with us. Our medical article is about Resiting and we would like to thank Mr Mark Gudgeon MS FRCS FRCSEd Consultant Colorectal Surgeon - Frimley Park Hospital, Surrey for his contribution.

Quite a few ileostomates and urostomates get in touch with Tidings so we have also introduced a new area within the magazine called Ostomy Community, in this issue ileostomate Clive Blanchard talks candidly about his experience of Ulcerative Colitis.

The Trustees have also been very busy this last quarter - attending events and speaking out on your behalf - at the Scottish Stoma Forum, Patients, Industry and Professionals Forum (PIPs) and on prescription charges at National Voices.

I hope you enjoy reading Tidings Spring Issue and if you have any ideas or suggestions for articles please let me know.

Email: editor@colostomyassociation.org.uk

Readers' Panel - Any reader who is successful and has an article, top tip or particular topic featured which results in publication will see this acknowledgement.



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space by
22 May
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publication early
July

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

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500 Club Winners

As well as raising funds for the CA the **500 club** gives members a chance of winning a quarterly cash prize. Here are the lucky winners...

- £796 - Mrs I Jones from Llanelli
- £398 - Miss Griffiths from Liverpool
- £199 - Mr Marsden from West Deeping
- £79.60 - Mrs Howe from Hove, Ms Robinson from Brightonsea and Mr Butcher from Stoke-on-Trent
- £39.80 - Mrs Chadwick from Ilkley and readers from Wokingham and Northwich
- £19.90 - Mrs Orlans from Altrincham, Mr Bartram from Yateley and a reader from Farnham.

Tidings is your Magazine...

Submissions:

If you have a story, article, letter or any other item you would like to appear in Tidings, please send them with any relevant photos or pictures to:

The Editor

Colostomy Association
2 London Court
East Street Reading
Berkshire RG1 4QL
or e-mail:
editor@colostomyassociation.org.uk

We will do our best to include them. Don't forget to supply us with your name, address, phone number and e-mail address, if you have one.

Supply of digital images:

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

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

FeedBack...We hope you have enjoyed this edition of Tidings and look forward to bringing you the next edition...We are always trying to improve your Magazine and welcome your feedback.

colostomy  association

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Recognising change...as a force for good the CA moves on again...



What a winter, so much
to contend with,
dark nights that seem
to go on forever and snow!
My worst experience was
getting back from a meeting
after a four hour journey to
Truro station and spending the
next three hours, stuck in the
white stuff, before finally
getting home. Thinking to
myself this can't be right it
never snows in Cornwall!

At last change is in the air and British Summer time is finally here thank heavens! They (whoever they are) say change is good and that nothing should stay the same, indeed even if we sit still, do nothing, change happens all around us.

It is on this note that I feel I must tell you of the changes that are afoot at the CA. Ray who has been the gentle, solid, stoical rock quietly and patiently guiding the CA to its current comfortable, stable, financial position has decided it's time to fulfil a dream that he and Beryl have had for several years now. Having been holidaying in Cornwall for some time they like me have come to consider it their home. Their dream has recently become a reality and I hope you will join with me in wishing them well on their new adventure.

Ray and Beryl have been the backbone of the CA for over three years. Ray who worked for NatWest and RBS for thirty-two years, became a Trustee and Treasurer to the CA in 2005, when the British Colostomy Association folded. Ray decided to take early retirement in June 2006 to take on the role of CA Office Manager. Beryl was persuaded to join as a member of staff, to help out in the office and on the helpline in 2006. She worked three days a week and was an empathetic ear for so many phoning for advice, whether it was a patient, a carer or someone who just needed to hear a friendly voice. Ray knows full well the role of carer, as he has been there for Beryl, supporting her through the challenges she has faced over the years. Beryl was born with an Imperforate Anus and had her colostomy formed when she was only five years old. Ray and Beryl's story was featured in Tidings some time ago; they are the proud parents of two wonderful sons, Robert and Steven.

I would like to take this opportunity to thank Ray and Beryl for their dedication to the CA at a time when

it needed just that. Their devotion helped to ensure that the CA became a recognised Charity grown out the membership's belief in its values and ideals.

I mentioned change earlier. After discussion and with the agreement of my fellow Trustees, I have resigned as Chairman, and the reigns have been taken up by the inimitable Monty Taylor, who I'm sure will take the CA forward. Coerced by Ray into believing myself capable of doing more for the CA in an Ambassadorial role, I have taken on the mantle and latterly I have been accompanying Ray to Patient Forums. Ray understood that only a colostomate could really ask the questions that needed to be asked of Government officials, Health Care Professionals and Appliance Manufacturers and distributors. I have entered a minefield of political meetings, all financially driven with not many championing the patients' real needs - choice.

Ray was delighted that I could become so incensed by some of the attitudes of others when discussing important issues that impact on and affect the lives of ostomates.

I get very annoyed when I am treated as someone who has a 'condition', I am like you a person and without being rude do not need 'them' to make decisions for me.

For example, at the Scottish Stoma Forum (Edinburgh Jan 09), there was a proposal that all ostomates should have an annual check up with their stoma nurse. My reaction was 'Why?' I hope I reacted correctly. I believe that every patient after their surgery should be assessed to see if they need to have an annual check up. At the six month check up this should be discussed with the patient. We all know that we can see our Stoma nurse for any reason. We can phone and make an appointment at any time. They will see us and allay our fears. How many of us want to see our stoma nurse each year? Isn't it for

us to decide when we see them (I nearly wrote 'her' then and there but bowed down to Colorectal nurse specialists in Cornwall and Devon much beloved by us in the South West!)

The cost in additional time to our precious nurses seeing those of us who don't need to be wasting their time is senseless, and to me an example of 'them' telling us what we need and not listening to our voice.

Ray and I went to two meetings that day, one hugely important in Scottish Government, thirty members around a table and me the 'newcomer', listening to Pharmacists and Government representatives clawing down the patients choice of where to get their supplies from. I admit to being the newcomer to all of this and not having a real understanding of everything that has gone before, but they have put questionnaires out to their patients to see if they are satisfied with the arrangements going on in Scotland. All the patients have signified that they are happy, why? Simply put, they don't know anything else. They don't know what products are available to them, and that they could or should have the choice. A choice that may make a real difference to their quality of life. They are in the hands of their 'guardian angel'; the stoma nurse and their hands are tied by Health Professionals dictating that they should only use a certain distributor or product.

It is all very complicated. Can you believe that the minutes from this Meeting still have yet to be circulated, still have yet to be seen by Government officials! I hope that in future issues of Tidings we shall get the opinions of the Pharmaceutical companies, the stoma nurses and the Primary Care Trusts (PCT's).

I also went to a meeting in the middle of Whitechapel, three underground stations later, I was frogmarched by Ray into offices

where a meeting of the Patients, Industry and Professionals Forum (PIPs) took place. Again more change affecting us!

It is a huge comfort to me to have the experience of Anne Demick of the IA and Hazel Pixley of the UA to fall back on. We have set up quarterly meetings in our offices in London Court to discuss how we as Ostomates should tackle these issues. We are intent upon being one 'voice' and thereby having more impact. It is hugely encouraging to know that although our Associations support different ostomates, ultimately we are all aiming for the same goal quality of life.

Recently, the Patient Associations were altogether at 'Revolutionising Nursing to Improve Healthcare' Stoma Care and Colorectal Education Symposium organised and hosted by Coloplast. This event talked about the importance of 'education' and 'quality of care for patients by nursing professionals' and that 'patient choice' was paramount. Built upon the content of the recent report by Lord Darzi 'High Quality Care For All' (available on the Internet) several eminent speakers shared their vision of the future of patient care within the NHS and some specialist speakers gave a real insight into their own intricate fields of work. Those attending were mainly stoma care professionals, it was an inspirational event and there is no doubt that by the end of the Symposium all who attended were empowered to take the message of 'quality and choice' back to their workplace.

Last summer, Ray was aware that more and more demands were being put upon him as Office Manager and he was struggling with increased workflow due to the recognition that the CA was getting as a result of 'Tidings'. He realised that this needed attention also there was an ever-increasing demand from new colostomates who really wanted to

help others. So he organised two Volunteer Induction Days back to back and thirty-two new volunteers came to Reading. It was very hard work! We admit we were not ready, but it certainly got us motivated!

As Ray moves on to Cornwall he will remain as Trustee and Treasurer. Myself, Monty and Jane Wood our Marketing Consultant, will manage the office with stalwart help from both Gill and Jo and our local volunteers. Monty and I will come into the office on a regular basis and Jane will be available two days a week as a first point of contact for manufacturers and suppliers. It will be helpful for Jane as she will be able to learn more about the workings of the CA and in doing so, will start to work on a marketing plan to raise awareness of the Association and its work.

Ernie Hulme will be more and more involved with our volunteers, and is at present working on several 'pilot' training schemes, with the help of Bob Buckley and Jean Scott these will build eventually into three CA accredited courses 'induction', 'telephone helpline training' and 'hospital and patient visiting'.

This year we will not be having a National Conference but instead will be concentrating on regional 'Open Days', dates and venues will be released shortly. So watch this space.

There is much to do and we must remain focused and positive so that we can continue voicing your concerns. We recognise that as a patient association we hold great sway and will work to bring it to bear for the good of all.



Sue Hatton
Executive Trustee
Colostomy Association

driving spirit Claire Bohr CNS paediatric stoma nurse bristol royal hospital for children



Open door is privileged to bring you an interview with award winning Paediatric Stoma Nurse, Claire Bohr - last year's Nursing Times award winner in the continence category. Claire was acknowledged for her ground-breaking work teaching children to use rectal irrigation.

Claire identified that transanal irrigation was used in Europe and the US but not in the UK, as no specifically designed equipment was available. Working with her medical colleagues and industry Claire came across a product known as 'Peristeen,' a purpose-made irrigation system recently introduced to the UK for adult use, by Coloplast. Claire investigated the potential of using the product in her work with childhood faecal incontinence, this driving spirit led to Claire winning her award.



A big thank you to Claire for opening the door to Tidings, for giving up her own time and for sharing her pioneering work with us - she really is making a difference to the quality of life of her patients and their families.

In the second of our series, Tidings interviews award winning paediatric stoma nurse Claire Bohr CNS



Claire began by telling Tidings about how she began her career and how she became involved with stoma care, there is also an extract written by Claire which explains why she pursued 'rectal irrigation' as an alternative to surgery for children with faecal incontinence.

Claire is based at The Bristol Royal Hospital for Children. The hospital provides a local service for Bristol children and a referral service for specialist care for families across the South-West and nationally. The current building opened on the 22nd April 2001 and was the first purpose-built children's hospital in the south-west. In April 2007, a further ward was opened to accommodate children's services from Southmead, with the long-term aim of centralising all hospital services for children in Bristol at one centre of excellence. The Bristol Royal Hospital for Children (BRHC) is part of the University Hospitals Bristol NHS Foundation Trust (UH Bristol) which includes seven hospitals within Bristol.

Claire began her nursing career as a state enrolled nurse or SEN; she felt

that her skills suited a more practical 'hands on' approach to nursing. Working in various nursing posts throughout the hospital and whilst carrying out her duties Claire began to take an interest in stoma care. She began to realise that the same stoma care nurses looked after both the adult and child patients. Claire realised that the care needed for children was very different to that given to adult patients, this was recognised by the hospital and Claire was given a blank canvas allowing her to develop a stoma care paediatric post. Claire mentioned that approximately ten years ago there were only a few children's hospitals that had paediatric stoma care nurses, Birmingham, Alder Hey and Great Ormond Street.

The age groups of the children under Claire's care can vary. Claire does not wear a uniform because she wants her patients to see her as very much a part of their family. Her patients may be new-born babies, toddlers and youngsters of primary school age or teenagers. Each age group brings its own unique challenges.

Babies who are referred to the intensive neonatal unit at Bristol may come from any part of the South-West region or nationally. An important part of Claire's role apart from patient nursing is to support both parents and family members, as it is often a struggle for them to understand the nature and implications of their baby's condition and some find it difficult to come to terms with the fact that their new baby is very poorly.

It can be an anxious and stressful time for all especially if parents may have to leave other children at home with family members and travel a long way to the hospital. The weariness that comes with trying to maintain family and work commitments in tandem with hospital appointments and visits cannot be underestimated.

Stoma formation in babies is generally a temporary measure and substantial corrective surgery may be needed due to one of the following conditions, Imperforated Anus, Hirschsprung's Disease, Necrotising Enterocolitis, Meconium Ileus, Inflammatory Bowel Disease. Some operations may be short term lasting several weeks, others several years, some may be able to be reversed others may not.

As far as possible, parents and other family members are encouraged by Claire to take an active role in the care of the baby. "Often with tiny babies they may have other life threatening conditions for example breathing and circulation. As the stoma is so visible, parents focus on the bowel condition and are encouraged to take ownership of the stoma, which can help bring them closer to their babies," Claire commented.

Today, there is a wide choice of stoma appliances suitable for babies and children, often a one or two-piece flexible paediatric or mini-stoma bag is chosen. These are more suited to the size and shape of babies. Skin care is important, alcohol based adhesive removers and skin protective

Claire developed a bowel management programme for young children who have congenital abnormalities, bowel dysfunction or chronic constipation



Claire pictured above receiving her award commented:

"I am thrilled to receive the award and hope that I'll be able to continue to raise awareness of this taboo subject, and support children using the treatment."

wipes should be avoided as the alcohol can be absorbed through the skin. Silicon adhesive removers should always be used to prevent the skin from stripping when removing the stoma bag. A young child will go on to other more defined appliances depending on stoma output and needs over time.

Most young children progress from nappies to potty and eventually achieve total control of their bowel, a major milestone in their development. However, for some children taking control of their bowel is sometimes difficult or often impossible. Faecal incontinence can occur in children because of a birth

defect or disease, but in other cases it's because of chronic constipation.

Claire has developed a bowel management programme for young children who have congenital abnormalities, bowel dysfunction or chronic constipation. Claire's work involves her working out treatment programmes for managing constipation and faecal soiling. These cover the introduction of toilet plans, dietary changes, or an increase in fluid intake. Some oral and or rectal medication may be required along with behavioural training and education for parents or carers.

If however, some children do not respond to any of these treatments and are not continent or have congenital abnormalities a surgical option may have to be considered, such as the formation of an Ace (Antegrade Continence Enema) or the formation of a colostomy, an alternative option which may be offered and which Claire has championed is rectal irrigation.

The following extract was written by Claire and explains how she became involved in pursuing 'rectal irrigation' as an alternative to surgery for children with faecal incontinence.

Taken from 'Rectal irrigation can be an alternative to surgery in childhood faecal incontinence'

"I was aware that a new purpose-made rectal irrigation system (Peristeen) was available for adults and I explored the possibility of using it with children".

Lack of evidence for new products is often a problem in paediatric nursing but I felt that using a purpose-made system rather than adapting equipment could benefit the children in my care.

When a new procedure is used in clinical practice it is important that the nurse follows the NMC (2008) code of conduct. It states that the 'professional is personally accountable for actions and omissions in your practice and must always be able to justify your decisions'. I was confident that I had enhanced my knowledge to practise in a safe and competent manner when I began to use the system with children.

I discussed using the rectal irrigation system with paediatric surgeons and a representative from the manufacturers (Coloplast). The system had one size of rectal catheter but the medical team felt that it was suitable for children to use. The volume of fluid used to irrigate the bowel also needed to be considered and, after discussion with medical colleagues, a volume of 20ml/kg was calculated to be a sufficient and safe quantity of fluid to establish effective irrigation.

I assess children with the consultant paediatric surgeon for suitability to undertake irrigation. They require manual dexterity, must be able to sit on the toilet and understand the time and commitment required for the procedure.

A DVD had been made for adult users and this was the only visual information available at that time, so it was shown to the parents first then the child. I provided additional information.

The child was taught the procedure so they are in control of treatment. They should be able to handle the irrigation system before they try to use it and their competence has to be carefully assessed".

**By Clare Bohr, RSCN
(Paediatric Stoma Nurse, Bristol Royal Hospital for Children, Bristol)**

Claire has since taught children as young as five to carry out their own rectal irrigation preventing them from having a surgical operation and improving their quality of life. The programme has had very positive results for the children in her care.

If a child does require surgery and rectal irrigation is not an option Claire will take time to chat with the parents and the child about the operation, she will also provide some carefully chosen literature, and put them in touch with support groups and regional groups. The hospital provides accommodation so that parents can be close to their child.

After the operation, Claire tries to put both patient and parents in touch with a child of a similar age who has been through a similar experience this can be very beneficial for the recovering patient. New technologies such as email and mobile phones play a part in helping with patient contact. Claire and her patients keep in touch, and she is often referred to as the 'poo' nurse! Claire says to her patients, "although you have to have a stoma you don't have to love it, just take care of it".

Children adapt quickly, especially if having a stoma makes a difference to them. Some may often become attached to their stoma and give it a name; if they have a reversal they may also need time to grieve for its loss.

Older children and especially teenagers may have had their stoma for sometime or have had surgery due to illnesses similar to those of adults, cancer, inflammatory bowel disease or trauma. The focus on and attitude to stoma care for the teenager moves away from that given to younger children.

Parents may sometimes make things more difficult for the teenager with a stoma without meaning to, as they can forget that he or she is no longer a child who requires constant input and protection. It may be helpful to give the teenager information and then discuss the implications so they can make informed choices. Respect of their privacy is also required and an understanding of what they may feel difficult talking about, also needs to be considered.

The Paediatric Stoma Nurses Group (PSNG)

PSNG is keen to promote best practice and provide a resource for those working in paediatric stoma care.

Mission statement:
The PSNG aims to promote excellence in practice for neonates, children and young people with stomas, by developing evidence-based health care and influencing national standards and guidelines.

Aims:
In order to deliver our mission statement, we aim to:

- support the right of children to access appropriately trained professionals in stoma care
- act as a resource to other allied professionals
- develop guidelines that are benchmarked and evidence based
- support the recommendations of the National Service Framework for Children
- develop a nationally recognised stoma care framework that benefits children and their families
- improve overall standards of care, reducing unacceptable variations in practice.

For more information contact:

Marie Waller, Clinical Nurse Specialist,
via Coloproctology, Stoma Care,
Box 207, Addenbrooke's Hospital,
Hills Road, Cambridge, CB2 2QQ

or on email:
marie.waller@addenbrookes.nhs.uk

Teenagers need to feel confident about common concerns, such as telling their friends and possible sexual partners about their stoma or fitting in with sporting or social activities. Claire particularly mentioned that teenage boys find disposal a real problem as often boys' school toilets like mens' toilets do not usually have disposal bins and she suggested that the manufacturers may like to consider some kind of disposal case for teenagers to carry with them at school.

As part of her remit Claire also visits schools to educate and liaise with staff and review school facilities. She also visits respite homes which care for children with special needs.

Claire is also involved with the Paediatric Stoma Nurse Group UK & Ireland (PSNG), which was set up in 2005 by Helen Woodcock from Sheffield. Today, it has between fifteen and twenty paediatric stoma care nurses throughout the UK. The group meets three times a year and at present members are working on a standards document for Paediatric Stoma Care which when finished will be presented to the Royal College of Nursing (RCN) for accreditation. Claire and the group are currently reviewing and rewriting patient literature.

At the end of the interview Tidings thanked Claire for her time, which was given outside hospital hours in her own time. Tidings asked Claire if she had a wish list for her post as Paediatric Stoma Care Nurse CNS to enable her to continue to do her work even more effectively.

And here it is...

- A room with a window
- Produce more specific literature for parents/babies/children/teenagers /schools etc
- A high quality digital camera to help her record her work in order to teach other nurses
- Visual aids for parents and children

Tidings hopes her wishes come true!

Editors Comment

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

Update on new stoma care products and services

Comfizz...Expand their Stoma Support Wear Range

- Unisex Boxer - High Waist
- Ladies Brief - High Waist
- Waistband - High Waist

All garments available on prescription, expanded range to now include sizes 2XL and 3XL which will fit up to waist sizes 56" or ladies dress size 36. Range now includes new neutral colour in briefs.



Unisex Boxer - High Waistband

Unisex Boxer (Waist Size)

S/M:	28"/30"/32"
M/L:	34"/36"/38"
L/XL:	40"/42"/44"
XL/2XL:	46"/48"/50"
2XL/3XL:	52"/54"/56"

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- **Breathable fabric** keeps skin cool, dry and comfortable
- **Reduces dragging feeling**- supports filling bag without restricting flow.



Ladies Brief - High Waistband

Ladies Brief (UK Sizes)

S/M:	8/10/12
M/L:	14/16/18
L/XL:	20/22/24
XL/2XL:	26/28/30
2XL/3XL:	32/34/36

Waistband Features

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- **Support** gives long term light support
- **Shape** improves body shape, smoothes bulges
- **Fashion** low rise trousers no longer an issue



Waistband

Waistband (Waist Sizes)

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M/L:	34"/36"/38"
L/XL:	40"/42"/44"
XL/2XL:	46"/48"/50"
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Email: lorraine@comfizz.com
Order online at: www.comfizz.com



If you have seen or heard about a product and you are not sure where to find out about it and want to obtain a sample why not email your query to cass@colostomyassociation.org.uk

Cuiwear

Cuiwear have just launched two new support garments for Ladies.

Ultralite is a new product that offers abdominal support. This product can be worn post operatively for abdominal support and to assist in preventing a hernia. Made from pure Cotton with 5% Lycra.

Fulciolite is a new medium support hernia brief for Ladies and offers comfortable support for a hernia that is small or has just started. This product can also be used as a preventative device to minimise the risk of a hernia in the first place. Both products have our patented in-built pocket to keep the stoma bag in place and away from the skin.

The above products are for Ladies and have 100% Cotton gussets. For more information, please see our advert on page- ????

Hollister

Hollister are pleased to launch a **new oval pouch**, available on prescription from March 2009.

This **one piece closed pouch** will be available in **maxi size in both beige and transparent film**. It has a soft flex skin barrier for flexibility and security, and includes the new AF300 filter.



Contact

Hollister Customer Services on 0800 521 377 for more details and to request a sample.
Opus Healthcare

NaturCare – Odour Neutralising SprayOpus



Now available as an aerosol. NaturCare contains enzymes that break down odour eliminating embarrassing smells rather than replacing them with a masking agent.

The aerosol is easy to use even when manual dexterity is compromised. Four versions of NaturCare are available on prescription: Unscented, Lightly Perfumed, Mint and Citrus.

Samples can be obtained by visiting www.opus-healthcare.co.uk or calling 0800 4587605

OstoMART

OstoMART are pleased to announce the latest innovative addition to the product range. As from 1st April 2009, the **new OstoZYME Multi** will be available on FP10 prescription.

OstoZYME Multi is a new presentation of **OstoZYME**, and comes in a 300ml pump action bottle, delivering an 8ml dose every time for the most effective use of any such product. **OstoZYME Multi** kills odour in the pouch, reduces static, prevents pancaking,

reduces noise, and also aids pouch emptying. The new bottle, with its measured 8ml delivery, will remove



any guesswork when using a product of this kind.

For samples of **OstoZYME**, please call **OstoMART Ltd FREE on 0800 220 300**

Product Code:

TCB3 - **OstoZYME Odour**

Neutralising Lubricating Gel - Box of 30 x 8ml sachets

TCB6 **OstoZYME Multi - 300ml Bottle**

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The **Combimate** range of flanges with their additional thin foam layer is designed to provide ongoing protection for the stoma during wear time as well as providing comfort, security and peace of mind.

For more information on the **Combimate** range of flanges, simply call the **Peak Medical** Freephone number **0800 652 0424**.

Look out for the new **1 and 2 piece drainable pouches with SoftSafe closure and finger pocket**. To be one of the first to try this super new product call the **Peak Medical** Freephone number **0800 652 0424**.

Have you tried a **new pouch or other stoma care product or service recently?**

Does my stoma need resiting?

Mark Gudgeon MS FRCS FRCSEd
Consultant Colorectal Surgeon
Frimley Park Hospital Surrey

It would be nice to think that once a colostomy or ileostomy has been created that it will work without problems for life. Sadly this is not always so and those with a stoma will know that complications occur in up to 70% of patients. Complications are often minor but some are more troublesome; they include skin problems, retraction, prolapse, parastomal hernia, fistula formation and leakage from a variety of causes.

Surgery to deal with complications carries a risk and it is therefore always essential to consider conservative (non-surgical) forms of treatment as the first option. Even when surgery is considered it is important to carefully weigh up the risks and benefits of the proposed operation before proceeding.

Stoma and skin related problems

Skin problems may result from ulcers, pressure sores and fistulas (abnormal connections between the skin and the inside of the bowel). Other causes include poorly fitting appliances, siting of the stoma close to scars or skin creases and an increase or decrease in weight. In most instances these problems can be managed conservatively with the help of the stoma specialist and many of the advanced appliances available today. Where conservative treatment fails and quality of life is adversely affected surgery is usually indicated. If skin problems are caused by a fistula, poor location of the stoma, a troublesome scar or skin crease then relocation of the stoma is usually inevitable.

Retracted Stoma

This occurs when the stoma sinks below skin level. Causes include technical difficulty especially when the stoma is created as an emergency, weight gain postoperatively and pregnancy. Retracted stomas often cause leakage with skin problems that are difficult to manage conservatively and frequently require refashioning but rarely relocation.

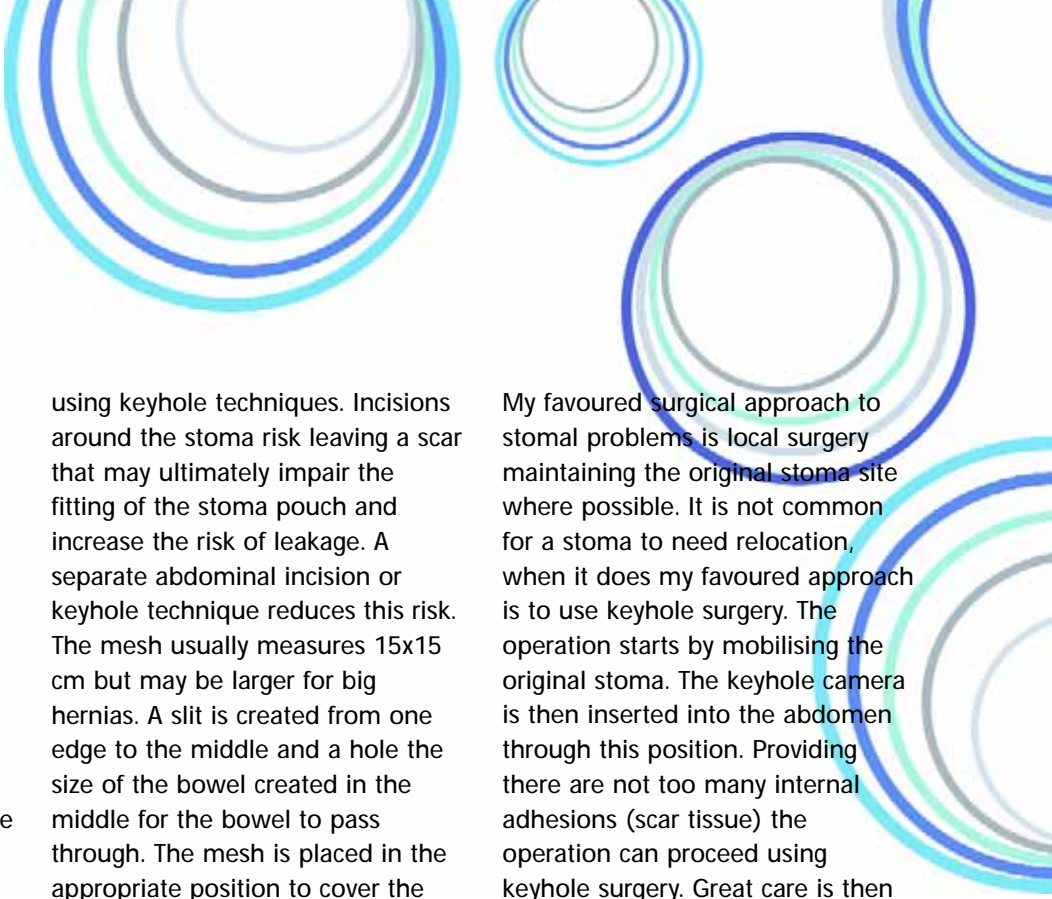
Parastomal hernia

This complication may occur in 30% of stomas or more, affecting colostomies more frequently than ileostomies or urostomies. Whenever a stoma is brought through the abdominal wall a weakness is created. The hernia occurs when the weakness in the abdominal wall is sufficient to allow the intestine within the abdomen to protrude through the abdominal wall around the stoma and into the tissue beneath the surrounding skin causing a bulge.

When making a stoma it is important to make a gap in the abdominal muscle, which is neither too large nor too small. The bowel has to be delivered through the bowel wall without constriction; if the hole is too small the stoma will have a poor blood supply and will not work adequately. If too big the development of a hernia is inevitable. In any event the defect in the abdominal wall is likely to increase in size with time. Studies are currently being performed to assess whether implantation of a mesh at the time of stoma formation will reduce the incidence of parastomal hernia.

What are the symptoms of a parastomal hernia?

You may notice swelling around the stoma that may be painful. It may result in leakage and skin irritation.



Sometimes the swelling can be large and cause an unsightly bulge beneath ones clothes. In rare instances it may cause severe pain and a blockage of the intestines.

What is the treatment?

If it is not causing trouble then no treatment is needed. Simple methods include use of a support belt and advice regarding choice of the correct appliance. If conservative treatment fails surgery may be needed.

Surgery

There are many types of operation which can be performed using traditional open surgery or laparoscopic (keyhole) surgery in order to make the abdominal wall fit snugly around the stoma. Three broad surgical techniques exist.

- 1 Simple repair of the abdominal wall with sutures,
- 2 Repair of the abdominal wall with reinforcement using a synthetic mesh,
- 3 Resiting of the stoma.

It is generally accepted that simply stitching and narrowing the gap in the abdominal muscles is insufficient in all but the smallest of defects. A synthetic mesh is used to reinforce the abdominal wall around the stoma and narrow the gap. This operation can be performed through a separate incision in the abdomen, by making an incision around the stoma or

using keyhole techniques. Incisions around the stoma risk leaving a scar that may ultimately impair the fitting of the stoma pouch and increase the risk of leakage. A separate abdominal incision or keyhole technique reduces this risk. The mesh usually measures 15x15 cm but may be larger for big hernias. A slit is created from one edge to the middle and a hole the size of the bowel created in the middle for the bowel to pass through. The mesh is placed in the appropriate position to cover the gap in the muscle wall and fixed in place using stitches or metal staples. Meshes are made from polypropylene with a special non-stick covering designed to prevent adherence of the bowel. Alternative meshes made from porcine collagen may also be used to repair the defect.

Stomal relocation is major surgery that involves either a large abdominal incision or a laparoscopy (keyhole surgery). The old stoma needs to be mobilised, the defect in the muscle wall repaired and then the bowel sufficiently freed from its attachments to be placed in the new previously marked location without tension. The point where the bowel is brought through the abdominal wall can also be reinforced with a mesh to reduce the risk of a further hernia. If relocation is performed for complications of Crohn's disease there is always the risk of those complications recurring.

My favoured surgical approach to stomal problems is local surgery maintaining the original stoma site where possible. It is not common for a stoma to need relocation, when it does my favoured approach is to use keyhole surgery. The operation starts by mobilising the original stoma. The keyhole camera is then inserted into the abdomen through this position. Providing there are not too many internal adhesions (scar tissue) the operation can proceed using keyhole surgery. Great care is then taken to ensure a good stoma is created in the position marked preoperatively by the stoma therapist.

Conclusion

Complications of stomas are frequent but often relatively minor and easily managed conservatively with a little professional help. When this approach fails surgery is indicated providing the person is fit enough for a general anaesthetic. A local approach refashioning the stoma plus or minus a hernia repair is the favoured option. Where persistent leakage, fistula formation or a complex parastomal hernia exists stoma relocation is indicated and wherever possible performed using keyhole surgery.

Frequently asked questions about the reactions of the stoma to what we eat



It is difficult to pin-point exactly why our stomas react as they do, to different types of food and so these questions and their answers can only give a general idea of how to manage diet. If you have a problem that is not answered easily by what you read – then you should contact your stoma care nurse or medical advisor to gain professional advice.

After an operation a part of the large bowel or colon may have been removed, thus making the digestive system shorter. This may affect the consistency of the faeces. Depending on how much of the large bowel has been removed the output could be anything between liquid, soft and formed.

Diet plays a large part in how we manage our pouch and its contents. While it is important to eat healthily, we may find that some of us are unable to eat as before, while others can eat whatever they choose. What an unkind world this is.

Remember – water plays a very big part in our diet. Food contains approximately 20% of our total intake – with fruit and vegetables having a higher water content than fatty foods. Try and drink a glass of water with every meal remembering that sometimes this can cause wind. While this may lead to more frequent visits to the toilet – it is important to remember the healing qualities of water. You may also find that the output could be a little more runny.

If you – at any time – find that your stoma is not working for a period of time and is causing you discomfort, stop eating and continue to drink water. Try drinking three glasses of water in succession. If you find that this does not encourage your stoma to work within an hour, then repeat the process. If symptoms persist contact your Stoma Care Nurse.

Note: Be aware – that if your stoma fails to work and you have no output while you are maintaining a healthy diet – contact your Stoma Care Nurse. It is always wise to report the lack of output, just in case it is the beginning of a blockage.

The following are the frequently asked questions about diet and the affect that food has on our stomas.

Q: Can I eat anything, now that I have a colostomy?

A: Within reason – the food that upset you before your operation is likely to upset you now.

Q: What food should I eat to keep a healthy stoma?

A: Try to eat a balanced diet that will include fruit and vegetables. Eat foods that contain protein, carbohydrates and foods that are rich in calcium.

Q: What foods could cause wind?

A: Generally speaking, these are cabbage, cauliflower, sprouts, onions, eggs, beans/lentils/pulses, fizzy drinks and beer and any kind of spicy food.

Q: How can I avoid wind?

A: By letting the fizzy drinks go flat. Try not to talk and eat, taking in air with your food. Keep to regular meal times. Don't use a straw to drink. Eating small regular meals may suit some colostomates and ensure that the stoma works efficiently. Other colostomates may prefer to "graze" eating when they feel hungry. Avoid large, heavy meals late in the evening. Try to avoid foods, which are high in fibre and unmilled grains.

Q: How can I avoid constipation?

A: Eating more fibre containing foods can help prevent constipation. Fibre acts by absorbing water to make the motions softer, so it is very important to drink plenty of fluids – at least 6-8 cups a day. Take gentle exercise. Drink fruit juice or prune juice.

There may be many reasons for constipation – i.e. medication, lack of mobility, and inadequate intake of fluids. If you do experience constipation you should get checked out by a medical professional.

Q: How can I avoid diarrhoea?

A: Pure fruit juices, some fruit and some green vegetables may cause diarrhoea to some people. Spicy dishes can irritate the lining of the digestive system and cause frequent motions. Prune juice, prunes, low calorie sweeteners and some

medication can also cause loose motions. Diarrhoea may be the result of a stomach bug, stress or an emotional upset. Antibiotics can also cause diarrhoea. If your output continues to be very loose, talk to your stoma care nurse about drainable pouches. This avoids the necessity of repeatedly removing closed pouches, so causing sore skin.

Q: How can I thicken my output?

A: Try the following, eat a very ripe banana, live yogurt, cheese, cooked apples, noodles. Boiled milk, rice, tapioca, smooth peanut butter and instant mashed potato are also good for firming up the motions.

Q: How can I avoid odour?

A: Odour can be caused by the foods that we eat. Fish, eggs, baked beans, onions, cabbage, garlic, asparagus and green leafy vegetables are a possible cause.

Talk to your pouch supply company about their products for eliminating odour. Oils, capsules, special filters – all are available to help lessen this problem.

As new ostomates, learning to live with our stomas and pouches, we all worry about wind, whether we will "smell", will "it" make a noise, and how to cope with this new addition to our lives.

Common sense will play a great part in managing your stoma and its' output. Very simply, what goes in must come out.

There is so much help, advice and support for you from so many sources. Ask your medical team for help and advice. or make contact with the volunteers of the Association, all of whom have stomas.

We are here to help – always.

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Pathways to a colostomy surgery in the USA and irrigation...



After over 30 years living with a colostomy it is hard to know where to start my story. I don't think much about it these days but, as I want to hear from readers with any problems they may have with irrigation, it seems only fair to share some of my background

From 1966 until 1985 I lived in the United States. In 1966 my husband, David, and our four year old twin daughters, went from England to Columbus Ohio so that David could be a graduate student at Ohio State University. We had intended to live in the US for two or three years but circumstances changed and we stayed.

This gives the background as to why in 1978, when I was diagnosed with colon/rectal cancer, I was living in Columbus. The tumour was positioned in such a way that a complete hysterectomy was necessary and the rectum was removed. The colostomy had to be permanent and I have always wondered if I would have been willing to have a reversal if one had been possible. I am not very brave regarding surgery and irrigating the colostomy has made it fairly easy to live with.

Having the surgery in the US there was never any discussion about not irrigating. You couldn't go home from the hospital until you could manage irrigating (which reminded me of not being able to leave hospital with babies until you had a feeding regime in place). I think it was three days after the stoma surgery that the stoma nurse started the training programme and within a couple of days I had learned the technique. This makes it sound easier than I found it as initially I was invariably sick when irrigating but after a couple of months this passed. I have now irrigated over 10,000 times but can still go through times when it is not easy or more often not completely satisfactory. However, I have never had a day when I have not irrigated – and if I am having problems there have been times when I have irrigated twice in a day.

In 1980 we moved from Columbus to New York City and I worked full time – in Columbus I had worked part

time as the children were at school. However, in 1983 I was experiencing some bleeding and was told that there was a tumour on the bladder.

At the first hospital I went to they said that they had never seen anyone survive a tumour of this size. I can remember getting up and leaving while the surgeon was still talking. It seemed to me that if he was so negative about my situation that there would be no hope of survival. So I found another consultant and his suggestion was to have chemotherapy and radiotherapy simultaneously. I was hospitalised for a couple of weeks and then continued with the radiotherapy and after a while the tumour was under control. I have been left with no sensation to urinate but that seems a very small price to pay.

Since then, thankfully, I have been well. However, in 1985 I decided to get divorced and move from New York City to London. I grew up in London, went to school there and until my marriage to David, worked in London. Leaving America was a big decision but on returning to London I worked in the City and in 1988 met Robin. We married in 1989 and in 1997 we both retired and moved to the Cotswolds.

A few of us with stomas soon started a support group for people with stomas living in the Worcester area. We kept it going for about four years but, sadly, with inadequate leadership it folded.

Sonia goes on to... describe her personal method of irrigation and her experiences...

Tidings is introducing a regular page on irrigation - so why not tell us about your technique, or any hints any tips and we will include them in the next issue.

Editors Comment

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

irrigation and me...

Irrigating is not for everyone with a colostomy. (you should always seek advice from your stoma care nurse) However, in the United States it is the routine way for people with a stoma to manage their colostomy. From the research I have done recently in Gloucestershire and Worcestershire only 2.5% of people with a colostomy irrigate.

I understand that this is probably about the national average. The stoma care nurses I have spoken to would be delighted to see more people irrigate but it seems that extra encouragement is needed. If you are thinking of irrigating do talk to your stoma care nurse to see if he/she feels that you would benefit from irrigation.



Photo courtesy of B Braun Medical Ltd

I am sure that there are many ways to irrigate but here is just one. Some time ago I read in Tidings an article mentioning the Braun Irrimatic Pump. I knew nothing about this and contacted B. Braun Medical Ltd and have now been using the pump for many years. The cost has come down over the years but it is still £260.64 excluding VAT. (If you are registered disabled you can claim back the VAT) To start with I was able to borrow a pump from my stoma nurse to see if I liked it enough to buy it.

There are other, less expensive kits available*. It would be sensible to use one of the less expensive kits to start



Photo courtesy of Hollister Limited

with, as undoubtedly not everyone who tries irrigating will find it satisfactory. The Braun Pump battery is charged by keeping it plugged in when not in use. This enables the water to be fed into the stoma as a constant stream.

The temperature of the water is crucial and this is where your stoma care nurse will help - (recommended temperature 37°degrees). My experience is that the water should feel really quite warm – but not burning hot.

I sit in front of the toilet and put a sleeve (which is part of the kit) in place round the stoma. Through a cone somewhere between 1.5 and 2 litres of warm water is then inserted into the stoma. This usually goes in quite easily and does not feel unpleasant. After a short time the peristaltic movement kicks in and the stool plus the water are expelled. This goes down the toilet. (Peristalsis is the automatic muscular movement, consisting of rhythmic wave like contractions, by which the contents of the alimentary canal are propelled along it.)

I flush the toilet every time there is some return. After about half an hour there is very little more to return and I put on a bag. Quite often there will be one or two more irruptions and each time this happens I change the bag. This actually means that my use of bags is possibly higher than someone not irrigating, but I don't know as I have never not irrigated.

It is claimed that it is advisable to irrigate at the same time each day, although I find that there is quite a lot of flexibility. I irrigate in the evening

but when I was working I irrigated in the morning before going to work. If I am going out in the evening and know that I am going to have dinner I usually irrigate before going out so that I know that there will be no return. I try to allow at least two hours from the time I start to irrigate until I leave home.

If you have any questions after reading this article, please send them to Jane Wood, the Editor of Tidings Magazine, and letters will be published in future publications and we will do our best to answer any queries you may have. These answers will be verified by a qualified stoma care nurse. I look forward to hearing from you.

Sonia Woolven

*Coloplast, Dansac and Hollister all sell irrigation kits and details of these can be obtained from the distributor you use for your stoma care supplies.

Patients who are suitable for irrigation should have:

- a left-sided colostomy either in the descending or sigmoid colon, with an output of formed faeces
- no stomal stenosis, prolapse or herniation
- a good prognosis and be free from other conditions, such as diverticula disease, Crohn's disease, ulcerative colitis or irritable bowel disease.
- physical ability to carry out the procedure, good eyesight and good manual dexterity
- good motivation
- the ability to learn and carry it out independently
- private toilet facilities with running water and adequate heating

References: Goode (1982), laucks et al (1988), MacDonald (1991), Davis (1996), Black (2000) and McPhail (2003)



Reader
PANEL
contributor

Travel Bag

Written by Leonard L

A confession

I begin this article with an obvious confession. I did not want to have a colostomy. It was, in fact, one of the greatest concerns of my life. However I think about it, the idea that I am now consigned to attaching, on a daily basis, various paraphernalia to a hole in my abdomen in order to make up for no longer having a rectum, that without irrigation I risk a bowel movement whenever my digestive tract fancies it, that even with irrigation I may still wake up beside my loved one unable to snuggle up to her because my bag is a bit squishy (you know what I mean) is not pleasant, even now.

Why do I open with such an obvious confession? Because I don't want anyone reading this thinking that I had an easy time of it. That travelling has been a breeze. I promise you – it has been far from easy. In fact it has been difficult, embarrassing, smelly and messy but it has all been really worthwhile.

I must travel

My colostomy was undertaken as part of my cancer treatment. I am in my early thirties. The surgery was followed by six months of sickening chemotherapy during which time I was invited to my friends' wedding in Australia. The chemotherapy was due to finish in April and the wedding was in August. I booked my flights in February.

If I can survive there then

The travel insurance was extremely expensive. I couldn't actually walk very well when I booked the flight –

the surgery still not having healed properly. I felt terribly sick every day and I had not yet started irrigating. I mention this because I want to emphasise that this was not an easy decision to make. I was not sailing through the whole process. I did, however, know that I wanted to get through it – as quickly as possible. I love travelling. I have travelled all my life. I could not imagine a world without it but I had no idea how easy or hard it would be now that I needed to organise bags, wipes, clean water, and clean conditions for changing. So what did I do? I decided to make things even more difficult for myself.

On booking my flights I asked whether there were any free stopover options. There were: Beijing, China on the way out; Bangkok, Thailand on the way back. I had always wanted to go to China and never wanted to go to Thailand but why not, it was free and it would break up the journey of flying direct to and from Australia.

My reasoning was that if I could survive China and Thailand I could manage anywhere and I really wanted to know what my limits were.

Preparations abound

Now I have another confession to make, I have a tendency to be paranoid. I am one of those people who need to check if the cooker is off three times before I leave the house. So just imagine what I was like when I was packing to leave.

I would be away for thirty days. That was thirty of all of the following –

bags, wipes, blue bags for waste and gauze pads. In addition, I needed my water funnel and removal sprays. But the advice I was given was to take twice as much as I needed. So I doubled that amount. But then I worried that maybe I might be delayed somewhere, stuck in a hotel or an airport, so I added a handful more. But I was also told to carry some supplies with me. Some. What does some mean. Three? Six? Twenty? Well in my case I just carried the same amount again in my hand luggage. Yes that's right. I mean, what if my luggage was lost, stolen, misplaced, kidnapped by aliens? So I carried sixty odd days worth of supplies both in my suitcase and in my hand luggage. And I did not just take the boxes. No – that would have been too easy. I packed each days supply neatly in a little blue bag so that every morning I could pull out one blue bag knowing that everything I needed for my morning routine was inside. It took hours. But I was ready.

Anything to declare?

Customs. Another worry of mine. The problem with colostomy supplies going through customs is, I have now found, twofold.

First the removal spray is marked as flammable – this usually raises some questions, which is not entirely unreasonable. The second is the funnel because it looks a little suspicious as it goes through the x-ray. I have spent a good twenty minutes explaining the need and use for each in various countries but, in conjunction with all the other supplies I carry, they are so obviously medical I have never experienced any real problems. (I guess I should also note that I look half Indian or a little Middle Eastern so customs is not the easiest place for me at the moment.)

So customs done, flight taken (as an aside: no your bag does not explode, implode, expand, or take on a life of its own that might somehow prove embarrassing while flying), and landing safely, I jumped in to a taxi and headed for Beijing. It really is an amazing city, well worth seeing.

Clean water in dirty Beijing

My next dilemma was clean water. Clean water in a city renowned for its pollution – yes I was a tad concerned. It had been almost 24 hours since I last irrigated. All was well but, already very proud of what my stomach had accomplished, I didn't want to test it any further. My taxi driver found my

hotel with only a minimum of aimless pottering round (one never knows if they are genuinely lost or trying to run up the meter). The concierge was very polite; I signed in, got into the lift and was shown to my lovely hotel room with an excellent view of the city.

Travel advice generally suggests that water in China is not to be trusted (it is not that it is not cleaned properly rather it is that it gets dirty traversing the old lead pipes of the city on the way to your tap). So you should always use bottled water to irrigate and guess what? One litre of bottled water is provided gratis every day by nearly all hotels in Beijing for precisely this reason. Of course they think you're going to drink it, not force it straight into your stomach but that doesn't really matter does it.

I spent ten fantastic days in China. Admittedly I did have to spend a day or two just laying around my hotel room because walking wasn't terribly comfortable but bar worrying about where to eat of an evening, everything was carefree, mineral water was available everywhere and the hotels were as good as, if not

often better, than those found in Europe.

Down below

Next stop Australia. The destination one might feel was of least concern of the three. Indeed the problem is not the facilities one might expect but the budget.

For what one might pay for a four star hotel in Beijing one will get a two or three star hotel in Sydney. This is fine except it actually makes managing ones colostomy needs a bit more inconvenient.

The hotel I had booked on the Internet was in fact a complete hole so I booked out again and found somewhere much nicer. Though the water is safe in Sydney I still used mineral water and once again all went well. My friends' wedding was attended and nothing untoward occurred. Not to say that my stomach had been perfect during all this time but nothing unmanageable (at least not that anyone else noticed – and lets be honest, that's what we really care about), and I even managed to flirt with a lady or two – after almost

a year of treatment that felt terribly good even if nothing were to come of it.

Bound to go bang!

Final destination, Thailand! It was bound to go wrong here, on a purely statistical basis. I expected lost luggage, delayed flights, problems at check in, the works. And what did I find nothing. Free mineral water in the bathroom, a clean room, and my reservation not forgotten. I had decided to stay for only three days because I had never really had any desire to visit Thailand but I wish I had stayed longer. The food was excellent, the streets and buildings interesting, the bars very modern, and generally it was a very amenable place.

And next

Obviously I got back to England safely and what did I do next?

Well lets just say that I have written this article in a beautiful little cafe in the middle of Buenos Aires, Argentina and, despite my paranoia, all is still going well.

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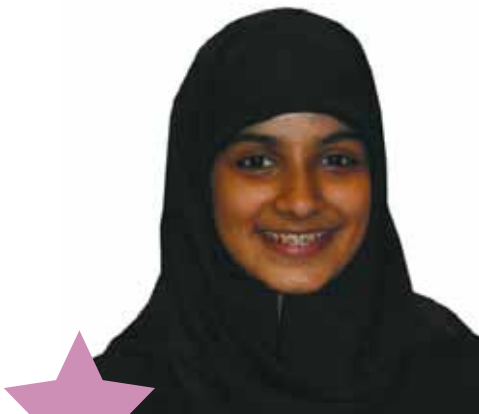
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Follow up on Salma's story from Autumn Tidings 2007

"having a colostomy has been the best thing ever as it has improved my life so much. I can eat, go out, have fun, without being worried and anxious all the time."

Salma writes about her colostomy and the best friend she met through the Colostomy Association and what this special friendship has meant to her



Salma pictured in 2007

My mum's advice of being patient has most certainly paid off. It has been over eighteen months since my stoma formation surgery. Now I'm 15 years old and two stones heavier. Everything has improved and progressed in my life. My education, my family, friend and teacher relationships. Most importantly and significantly my health. Since having my stoma formed I have gained the weight I lost and more to the point, I actually hit the teenagers' average weight line on my dietician's chart. A couple of months back, just as I settled into the summer holidays I experienced a rerun of the summer of 2004. I felt a horrid shooting pain, and was on the verge of an emotional breakdown.

The thought of going back to square one was horrid. What if everything that I had been through was a waste of time? The thought was terrifying. The only different thing this time was that I didn't hesitate to get myself checked out by the hospital. Nor did the doctors hesitate in booking me for an emergency examination. I, along with my parents feared the worst.

My fears were soon allayed. The doctor told me the horrid shooting

pain was simply the shrinking of the abscess, which was 'suffocating' the sutures. One suture was removed leaving one left behind. For the first time in four years a feeling of relief overwhelmed me! I had waited so long for this moment and a warm rush of adrenaline flowed through me. I was swimming in the pool of freedom, freedom from a depressing illness, which I was beginning to overcome.

I was quick to break the news to a dear friend. Someone I met up with a year back through the Colostomy Association. It turned out that Dot who is 19 was also from Bradford, and had the very same condition as me, right down to the position of our abscesses! What are the chances of that? We both met up after writing to each other for a few months. The friendship and understanding between us is really precious and unique. We can talk openly about everything and share our experiences and we confer on different situations we find ourselves in. This has helped me on numerous occasions.

I now know that I'm not the only one in the world experiencing a similar situation. I have someone who I can share my worries and anxieties with. For that I am extremely grateful as not everyone has a friend who can really understand his or her problems. My best friend Dot has really made a difference to my life; she has certainly helped me through and has made it a whole lot easier for me to deal with my situation. Without the support of Dot and the care and nurturing from my parents, teachers and nurses, the past 4 years would have been made more difficult.

Next week it will be 2 years since I had my colostomy. Most people that have heard about a colostomy or know somebody with one always assume that it is a bad thing. But for me it has been the best thing ever as

it has improved my life so much. I can eat, go out, have fun, without being worried and anxious all the time.

At the moment I'm in year 11 and will be doing my GCSEs in roughly a month's time. I've still got my colostomy for at least another year (or less I hope). I just can't wait till I have fully recovered from Crohn's Disease and have my colostomy reversed because then I won't have any hospital appointments or admissions to attend nor will I have to always plan my life around my health problems, instead I can plan things around me.

Tidings asked Salma what she would like to see on this page..."I would like something like a teenage agony aunt to whom you could write in to about stoma care problems, be at home or school. Also I would like there to be like a small 'tips' section with hints on how to cope with your stoma at school in exams etc".

Editors Comment

If you have any suggestions for the young colostomates page get in touch via e-mail: editor@colostomyassociation.org.uk or write to: Colostomy Association
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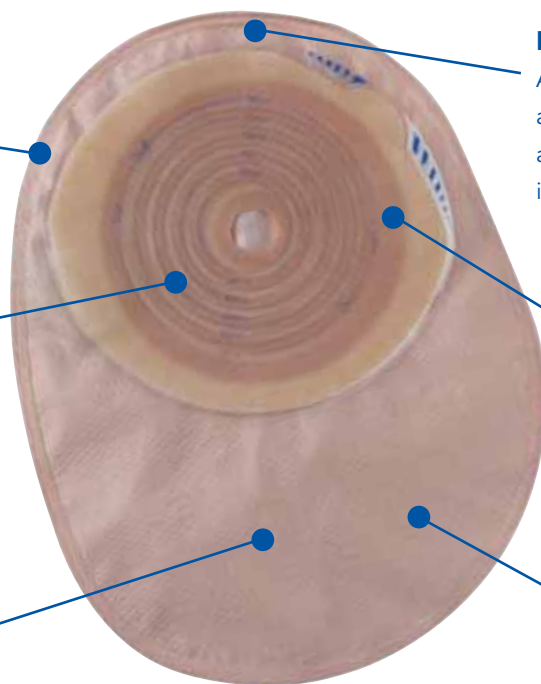
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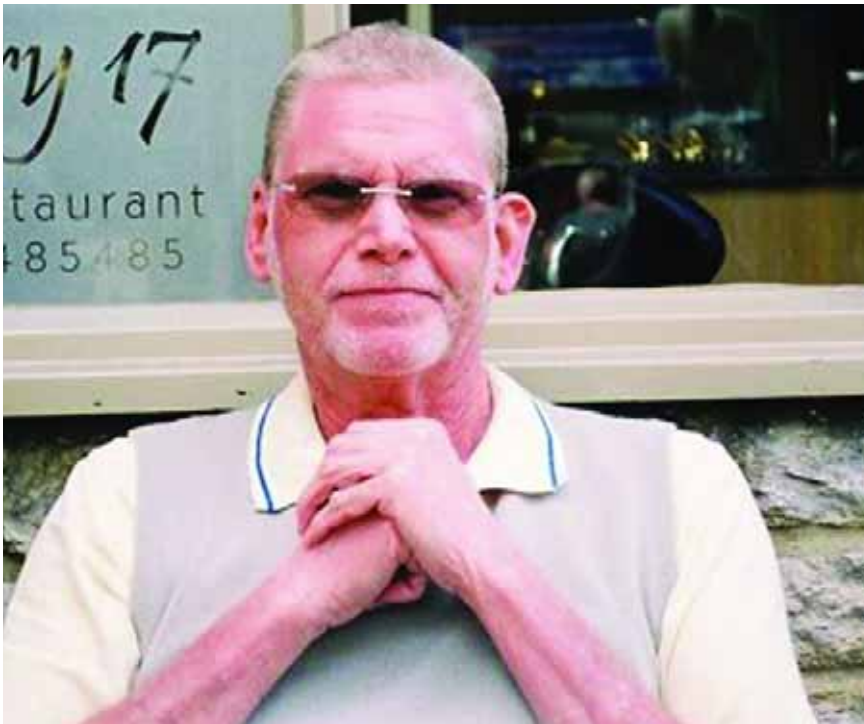


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Speaking out... "I would like to encourage other ostomates to talk about their experiences because over time it's helped me."

I know Tidings is the magazine especially for colostomates, however I thought you may like to read about the journey of an ileostomate.

My problem was Ulcerative Colitis (UC for short), an inflammatory bowel disease which was first diagnosed around 1995, prior to which I'd had diverticulitis. The cause of UC is not entirely known; a small number of UC cases do develop into bowel cancer, depending upon the duration, location and severity of the disease. Symptoms include bleeding ulcers, pain, soreness, cramps and an uncontrollable urgency to use, and therefore absolute need to always be near to, a toilet. It is a debilitating illness which over time becomes a living nightmare, as anyone who has had UC will testify.

The symptoms of UC were treated by a combination of drugs. Obviously Immodium became my staple diet! In

addition, initially Asacol and then Azathiaprine were prescribed. The steroid Prednisolone was added, with Amitriptyline, an anti-depressant which should have a calming effect upon the bowel. Finally I was prescribed Cyclosporin, which is an anti-rejection drug used by transplant patients. At its best, when the UC was in remission I was taking maybe a dozen tablets every day, however at its worst in excess of thirty, a mix of all the drugs I've mentioned.

Unfortunately and all too frequently, even that little lot didn't bring the UC under control. On two occasions the Prednisolone and cyclosporin were administered intravenously in hospital, fortnightly stays each time. That had a very short term beneficial effect, but inevitably, it was back to the tablets! How can I forget the foam and water-based enemas! Most sufferers of UC will tell you that it's almost impossible to retain the

enema anyway, so they were to all intents and purposes no use at all.

Then of course there were the regular sigmoidoscopies, colonoscopies and other embarrassing and uncomfortable examinations. Whatever dignity I had, didn't last too long.

Irrespective of the drugs regime, most days I was visiting the "little room" as many as 25-30 times a day, sometimes more. I recall that statistic well because my consultant asked me to keep a record of when I went, with all the glorious details! The discomfort and exhaustion of these visits to the toilet made everyday life a misery. I was taking time off work or at best getting in to the office mid-morning. One aspect of my work included travel to other Company sites, so motorway service areas were planned in minute detail for toilet stops. On the home front, my involvement with my sons' sport was curtailed, I couldn't watch my favourite football team or visit my family because both involved 180 miles of travel. To all intents and purposes I became housebound and my life was on hold, in nearly all respects.

My boss was a very understanding chap, what you'd call "a people person". He promised to keep my job open for me whilst I was away and was always true to his word. I couldn't have asked for more support as the time I was having away from work increased. Thankfully I had a great team working with and for me. Eventually, however, such was the overwhelming effect of the symptoms that I realised I couldn't do myself, my boss, team or work justice and was falling short of the standards I set myself and my team. In the end I realised it was necessary to take early retirement. All through this my gastrointestinal consultant insisted that surgery had to be the absolute, last resort.

I'd heard bits about "having a bag", but only negative stuff, with the associated stigma and less-than-nice connotations. I'd heard of a "stoma" but didn't really know what one was or understand even the basic principles. As I say, all I was ever told was that "surgery must be the last resort". I suppose I was afraid to consider it seriously and therefore consciously blocked it all out.

“One day I just blurted out how I felt when I was being checked over in the SCD. Most of the demons were laid to rest that day, as the staff encouraged me to talk through how I felt and they helped me to put everything into clear perspective. That was important as I feel much of living with a stoma is about confidence.”

About twelve months after I retired however, it became clear that all the drugs wouldn't help or eliminate the UC. I figured I had two choices – to carry on as I was, or deal with the disease head-on, once and for all, in the hope of attaining an improved quality of life. So actually there was no choice, was there? At my request, my consultant referred me to the Stoma Care Department (SCD). That's where my wife and I heard the facts - what the surgery would entail, the end result, risks, benefits, on-going support, appliances, psychological implications, body image – the whole picture. Although I'd already pretty well made up my mind that I'd go ahead with surgery – anything to end the daily misery – the facts forced me to think it all through again. I reached the same conclusion though – no going back!

Within weeks I'd seen the surgeon, who discussed with me many of the areas previously covered by the Stoma Care Department. He talked me through and explained the total colectomy operation he'd be performing – removal of the large bowel, rectum and anus – which would result in the formation of a permanent ileostomy. Three weeks later, I was placing myself in his and his team's expert hands. Goodbye large bowel, but goodbye UC!

I was never nervous about the surgery. Perhaps I was just so relieved to be given the opportunity to be free of UC, to get my life back. Just do it, get it over with! Sounds melodramatic maybe, but I'm sure any other UC sufferers would say they probably felt exactly the same.

I was pretty lucky with the operation and healing process. I'd seen what a stoma looked like in photographs and wasn't too concerned when I awoke from surgery to see mine. The biggest problem was “getting going” again

and the physios gave me the encouragement I needed to get cracking pretty quickly. I had tuition from the SCD regarding changing the pouches and how to take care of my stoma and left hospital after ten days.

I won't pretend I found it easy after leaving hospital. I struggled confidence-wise with changing the pouches. My wife was a fantastic support in this respect but I was reminded by my stoma care nurse that until I completed the whole process of changing the pouch myself, on my own, I was not truly independent – which of course I should be. There were other issues I faced in the first few weeks and months including:

- Phantom “toilet sensations”: these feelings of needing the toilet were frequent but I was reassured they were very normal. On more than one occasion I actually went upstairs to the bathroom, forgetting I obviously had no need – much to the obvious amusement of my sons!

- Soreness of the skin around the stoma: this became inflamed due to the stoma output coming into contact with it. The solution was simple - check the aperture in the pouch is the right size for the stoma! It's apparently a very common problem, resolved by spending an extra couple of minutes checking the aperture size. The skin was very quickly healed by a combination of accessories – all available on prescription.

- Parastomal hernia, around the stoma. These are quite common but nonetheless can be troublesome when changing the pouch. The hernia can sometimes prevent the pouch from being placed completely “flush” to the skin, but I overcame this reasonably easily with the use of stomahesive paste or using a different variation of my pouch.

- Leaks! I was warned they would happen but didn't believe it. I went ages without a hint of a leak, then

two occurred out of the blue. The first major leak was when I was staying at a hotel. I felt embarrassed and ashamed, but my family was great, so supportive and helped me to quickly learn, as everyone else does, that accidents happen. It's no use worrying about them, get on with it and get used to the fact that it'll happen again.

Dealing with the emotional and psychological aspects of this major change in my life was something of a challenge too. This was more difficult because I'd always felt I was independent and could cope with anything. It was embarrassing to admit I was struggling to come to terms with everything. Everyone said how well I was doing and appeared confident in my approach to the new regime and way of life – but it didn't feel like that at the time. I tried to place it into some sort of perspective; could it really be anywhere near as bad as all the drugs and their side-effects, as bad as the sigmoidoscopies, colonoscopies and other examinations I'd had pre-surgery, while suffering with the colitis? Well, yes actually, that's how it felt.

Eventually, one day I just blurted out how I felt when I was being checked over in the SCD. Most of the demons were laid to rest that day, as the staff encouraged me to talk through how I felt and they helped me to put everything into clear perspective. That was important as I feel much of living with a stoma is about confidence and I take considerable comfort from the fact that if I do have any problems, there are highly trained and skilled staff that should be able to help me.

By now, I was learning fast, realising I was far from unusual because whatever physical or emotional issues I had, many others have too. Most important of all, I realised for most problems, there's a pretty quick and effective solution!

Speaking out...

I was never concerned about whom I should tell about the surgery and the fact I now had to permanently wear an appliance. Family, friends and work colleagues all knew I had UC, so when they asked me about the surgery I told them what was involved, and the resultant need to wear a pouch. I adopted the approach of telling someone if I felt I needed to - I'm always entirely honest and open about my stoma and it does not embarrass me.

I also take the opportunity to educate people! Everyone who refers to it does so in terms of a "colostomy bag". In their innocent ignorance they don't realise there's such a thing as an Ileostomy and Urostomy. So I try to explain, if the subject is ever discussed, that there are different sorts of stoma, pouches/appliances etc., and how and why they're all different. Hopefully, the more educated people become, the less of a stigma there'll be surrounding our "bags".

So, here we are, six years on and it's a good time to reflect upon how my ileostomy has affected my life – or rather, after those years of UC, my quality of life.

The first four and a half years were relatively problem-free and I settled into a good routine of changing the pouch every other day. I was initially cautious about emptying the pouch when out and about but found the toilets available through the RADAR scheme to be very good. I began driving longer distances again without the worry of planning my journey around toilet facilities and returned to watching my sons playing football and cricket. I can now sit through meetings without leaving the room several times and eat pretty well what I want, when I want. Thankfully I now only take a very limited amount of medication, and this is not related to my stoma.

Pre-surgery my weight had ballooned to 16 stones, due to the medication and my lifestyle. Much of the excess was quickly shed – it needed to be! – but it meant I became fitter and healthier than for many years. I walked every day in preference to using the car. One of the strangest

things was coming to terms with all the additional time I had on my hands. Think about it – 25-30 trips to the toilet per day I was no longer making! I once did a rough calculation and I think it saves me about 2 hours a day. There's time and motion (pardon the pun) for you.

I've not returned to full-time employment. Helen, the current Mrs B, had been through two bouts of breast cancer, so I decided to spend some quality time at home and do voluntary work instead. Mid Essex Stoma Support (MESS) was formed by one of my stoma care nurses, Nikki Saunders, who invited me to get involved with MESS, which at that time was in its infancy with about 35 members. Six years on, we have a membership of 240 and organise a number of events annually, including coach outings, buffets, Christmas Dinner, ploughmans supper and other meetings. The organisation involved can be time-consuming, but it's a productive way of using that extra 2-hours-a-day I suddenly found!

Another rewarding aspect of my involvement with MESS is the opportunity to educate non-ostomates and spread the word about what it's like to live with a stoma. Nikki has invited me to talk to student nurses at the Anglia Ruskin University and other volunteers on several occasions; I have no doubt that education is an important factor, especially within the health profession, because as many of us have come to realise, the majority of those working with the NHS have very little, if any understanding of the different types of stoma and ostomates' needs.

On a personal note, unfortunately the last eighteen months or so have been a little less straightforward. As a small parastomal hernia grew I experienced more leaks which made the parastomal skin sore. With advice from the stoma care team, I tried a number of different bags and found some security and routine in using soft convex with flange extenders. Eventually however, the hernia became sufficiently large as to require surgery.

Unfortunately, the surgeon advised re-siting of my ileostomy from my right, to left side. So November 2008 the surgery was carried out, giving me the opportunity to make a fresh start, with a new stoma. I've been very good post-surgery, resting sufficiently to allow the surgery to 'settle' and give everything the opportunity to heal internally.

To conclude, I've come quite a long way since the days of fortnightly hospital appointments, those awful examinations, living in the toilet, in constant discomfort and a diet comprising more drugs than food! Despite the permanent ileostomy I still consider myself to be very lucky. Why? Well, firstly my surgery was elective; irrespective of the health and quality of life issues I had at the time, I chose to have my surgery. I didn't face an immediate life-threatening illness such as bowel or bladder cancer, sufferers of which don't have a choice.

Secondly, any progress I've made in attaining a better quality of life has only been possible with the help and support of many people in the medical profession, and my family. Day in, day out my wife and sons have been at my side. They were there when I needed them most; they put up with my mood swings and ill-temper when I was suffering with the UC. They have been there for me post-surgery both times and have put up with me when I had bad days. I know I was not easy to live with at times. Actually, they'd probably argue that not a lot has changed! Seriously though, they've all been fantastic and I don't know what I'd have done without them.

Clive Blanchard

Editors Comment

I would like to thank Clive Blanchard for giving us an insight into his experiences and would encourage you to speak out.

You get in touch via e-mail: editor@colostomyassociation.org.uk or write to:

Colostomy Association
2 London Court East Street
Reading RG1 4QL

Have stoma will travel... life on the high seas



Tidings often features colostomates who, with their stoma, have bravely traversed the four corners of the earth. We have featured mountain climbing expeditions, trips to Europe and the good old US of A, travel to exotic places like Thailand, not to mention visits to countries that have only fairly recently allowed tourists across their borders e.g. China. Many of you have travelled via air, sea, and overland, and must by now have covered thousands of miles between you. How fantastic is that...

Recently, we have had a number of colostomates who have been in touch to say that their preferred holiday takes the form of cruising, here are a few pointers on planning a cruise and a fantastic readers' experience.

So, why go on a cruise?

Travellers nervous of flying often choose a cruise. The advantage of cruising is that passengers are not restricted on the quantity of luggage they can take which is a great relief for ostomates who do not want to be separated from their stoma supplies. Cruising is simply a great way to travel. You have all the benefits of home, a secure, comfortable and sociable environment, with an added bonus, your home or hotel in this case moves with you, allowing you to visit many different places virtually hassle free.

It is possible to cruise all year round in Europe and the Mediterranean with itineraries covering destinations from Scandinavia in the north to North Africa and the Middle-East in the South. There is much more choice in the summer months as demand is higher, and some itineraries do not run during the winter. Passengers can catch a flight from almost anywhere in the world and join their ship in a major port such as Dover or Barcelona.

Planning and research

When planning and booking a cruise it is essential that you research what is available for your budget, the size of ship you choose can make a big difference to your cruise experience. The Internet is a valuable source of information about cruising, most of the cruise lines have their own websites, which supply information about their current programmes. Some sites even offer a virtual-reality

tour of a ship. If you don't have Internet access there are a number of travel agents that specialise in cruise holiday packages and you can always contact travel associations for more information. Cruise operators often place adverts in the national press and Sunday supplements.

One of the golden rules of cruising is to shop around, as the cruising market is highly-competitive, discounts and early-booking plus a whole raft of other incentives are available. You can also find out more about cruising by visiting the annual Cruise Exhibition, which takes place early in the year. This year's event has only just finished and was held at the ExCel Centre, London. The exhibition brings together small specialist operators, travel agents, tourist offices and cruise lines under one roof. Leading experts can help you gather impartial advice and you may even find one of the many exclusive offers only available at the show suits your budget. The Daily Telegraph sponsored this year's event, so it may be well worth putting a note in your diary for next year.

Just the ticket?

Cruise prices may and at first glance seem expensive, but, given that they include accommodation, all meals, many non-alcoholic drinks, transportation, entertainment and in some cases trips ashore, it must be said that they offer real value for money. Most cruise companies will state what is included in the price and, by law, advertised charges

Have stoma will travel... life on the high seas



should include all pre-payable taxes, such as passenger service charges. If flights are part of the deal, then the airport tax and airport and port transfers should also be included in the price. Usually passengers should expect to pay additionally for holiday insurance, alcoholic drinks, port taxes and shore excursions. Some cruise lines offer 'all-inclusive' deals, which means that all gratuities and drinks on board are included in the price.

Choosing your accommodation
If cruising for the first time passengers should be wary of terms such as superior or deluxe. Some ships will simply have a better standard of cabins across the full range of cabin grades than others, so the best way to guarantee value for money, and that the cabin is up to standard, is to simply compare like with like when looking at brochures. As a rule of thumb, larger ships offer a wider choice of accommodation. The more you pay, the larger the cabin and the better its position. Economy accommodation is often a small cabin in the depths of the ship, with two berths and a bathroom.

Tips for choosing a cabin

- Study the ship's layout and deck plans very carefully.
- Select the best cabin you can afford
- The higher price for the outside cabin is always worth it
- Newer ships often have cabins specifically designed for passengers with disabilities and on most decks there are readily accessible disabled facilities.
- If you find that the ship is not fully booked, enquire when boarding what the cost is for upgrading on the spot to a better cabin or suite.

Facilities

The cheapest cabins will include two single beds or an upper and lower berth a ladder is provided for access. The bed frame usually tucks away out of sight during the day. There is usually an en-suite bathroom with shower, toilet and wash basin (towels and soap are always provided). Disposal of used bags is not a problem. Although "flushable" bags must not under any circumstances be flushed down the WC of a ship as this works on a vacuum system with small diameter pipes and the consequences can be a disaster if blockages occur. Used bags, once emptied are placed in the bathroom waste bin in the same way as sanitary towels.

A cabin is usually furnished with a chair and table, a combined vanity and desk unit and storage for suitcases. Life jackets for each person and instructions on how to use along with other emergency measures are posted in each cabin. There will be some form of air-conditioning and electrical outlets. There may also be a telephone and television. The higher grade cabins are usually larger with more space and larger beds and more furniture. A crew member will clean and tidy the cabin and make the beds each morning.

Documentation

Carrying the right documentation It is essential when considering booking a cruise that you check well in advance that all the correct documentation is in place. Tickets, passports, visas, travel insurance, health requirements, credit card and so on all in order. It is important to obtain any visas that may be needed for some of the countries on the cruise itinerary so that you don't miss out on any shore excursions. Travellers should note that visa

requirements do vary according to the nationality of the passport holder. Photocopies should be made of all documentation and the copies should be packed separately from the originals, they will be invaluable in the event of any problems later.

Passports and boarding passes

When you check in for your cruise the normal procedure is for the Purser to retain your Passport and give you in exchange, a boarding pass and cabin key. Boarding passes may have your photograph displayed and are used when you go on visits ashore, great care should be taken of your boarding pass.

Medical matters

Most cruise ships have a qualified doctor or nurse on board – their services may incur a charge, but holiday insurance will normally cover this. Ships carrying more than a 100 passengers are also likely to have a small hospital below decks. Forward planning is essential on any trip you are likely to make, working out what stoma supplies you need to take with you while you are away will give you peace of mind and will not distract you from enjoying your holiday. If you are cruising in Europe you are never more than a few hours away from shore-based medical facilities. Don't forget to get your travel certificate signed and keep in to hand should it be needed.

readers' experience
of cruising

travelling the easy way....



Owa Zulu Natal

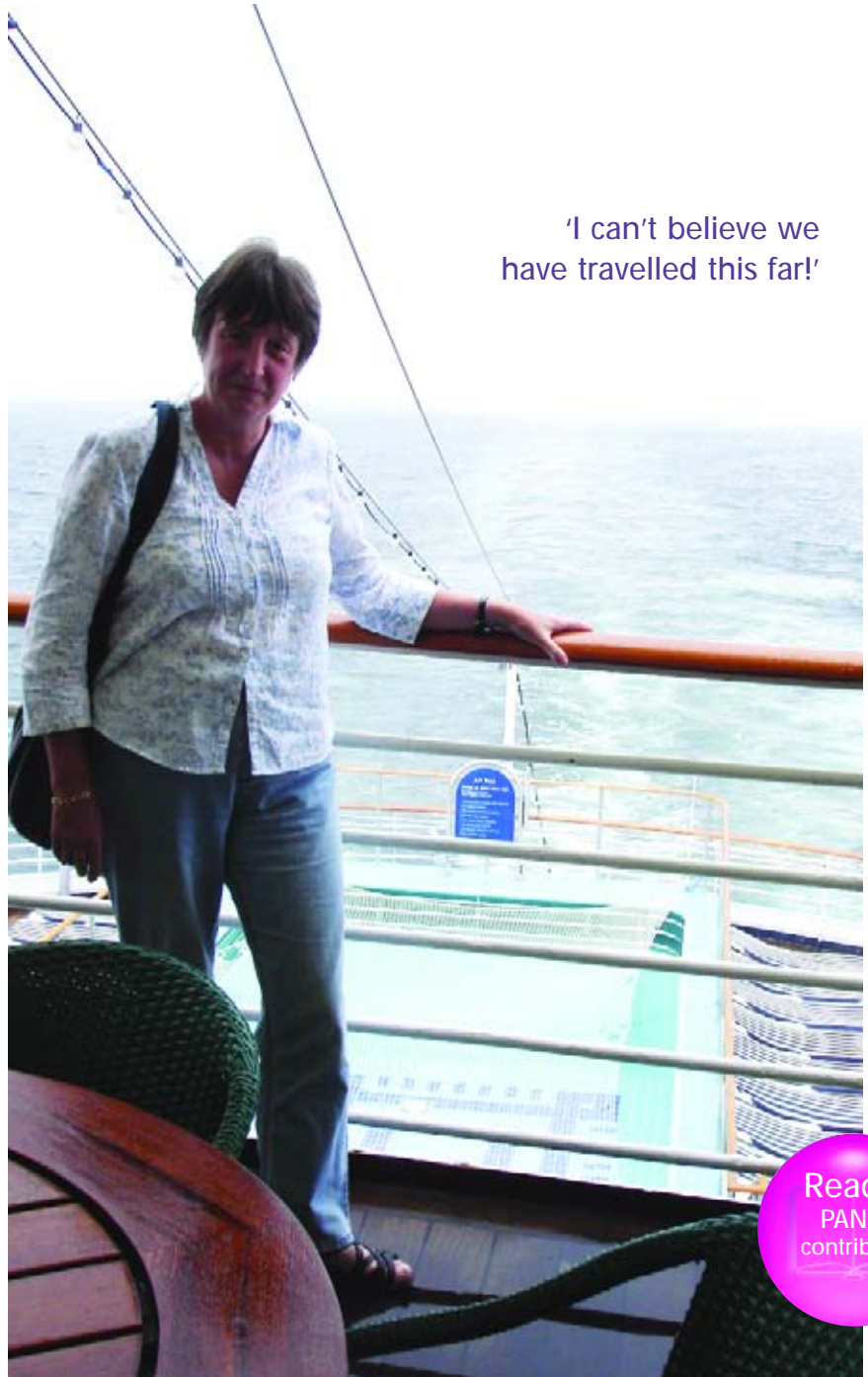
A game reserve in Owa Zulu Natal. 'I had to pinch myself to make sure I was really there.'

Before I had my stoma I'd only been abroad once: a disastrous package holiday in Spain where I spent several days in hospital suffering from the bowel condition that led to my colostomy three years later.

After the operation I looked down at my stoma, the boxes of appliances needed to manage it and thought, 'Well, I'll never travel anywhere now.' How wrong I was.

In 2008 I stood on the top of Table Mountain and gazed out over the South Atlantic and down to the city of Cape Town far below. Three days later I careered along rough tracks in a 4 x 4 looking for elephants, monkeys and giraffes at a game reserve in Owa Zulu Natal. I had to pinch myself to make sure I was really there.

Believe me, I'm no backpacker or a spring chicken. Our travelling is done



'I can't believe we
have travelled this far!'

Reader
PANEL
contributor

the easy way aboard a cruise ship. Wherever we go we take our bedroom - and our bathroom - with us!

Five years after my stoma was formed I got married again, but it would be a further five years before my husband could persuade me to venture abroad. We started with a cruise up the Baltic Sea to St Petersburg. The trip started and ended at Harwich so there was no need to fly.

Like all ostomates, I was concerned about how I would manage my colostomy on the ship. What would I do with my used appliance? I just did what I do at home: emptied the bag

and put it in one of the disposal bags provided by my supplier, but then, for extra discretion, I placed this inside one of the paper bags labelled "For Disposal of Feminine Products" that I found in the en-suite bathroom, before I dropped it in the bin. I have since discovered that if you tell the staff in the medical centre that you have a stoma they will provide you with a clinical waste bag which will be collected from your cabin and I know many ostomates would prefer to do this.

My other worry was the shore excursions. What if I needed to change my bag? Would I be able to find a toilet? I needn't have worried.

readers' experience
of cruising

travelling the easy way....



En-suite...you take your bathroom with you!

There is always at least one comfort stop even on a short, three hour outing – but remember to carry some small change in the local currency for the attendant who may be sitting at the entrance holding out a saucer.

Our next cruise was to the Mediterranean, leaving from and returning to Southampton. I was still adamant I wouldn't fly – thousands of feet up in the air, no thank you!

Then came the opportunity to cruise round the Far East and back home through the Suez Canal. It would mean flying to Singapore. Well I suppose I'd get the aeroplane bit over right at the start and could enjoy the rest of the holiday. I have to say that I hated the flight, but that's just me. However, I had no problems at all with the bag. It didn't balloon: I think this myth all stems from when ostomy appliances didn't have filters. Nowadays "bags blowing up" only



Cruise ship docked at The Waterfront, Cape Town

happens if the filter doesn't work, so if you normally use a cover leave it off and it's a good idea to change your bag before you get on the plane to ensure the filter hasn't got damp which can make it less effective.

I didn't need to change my bag for the whole of the thirteen hour flight (we were delayed by two hours) but I checked out the toilets and, although they're a bit cramped, if I'd needed to I could have managed. I would just have disposed of the used appliance in the bin labeled "Nappies".

'Well, if you can manage to fly there you can fly back as well,' said my husband. So last year we flew out to Cape Town and cruised around the Cape of Good Hope then up the east coast of Africa. And yes, I did manage to change my bag in the loo at the top of Table Mountain!

We have now been on six cruises and spent a hundred and fifty two days afloat. 'Have I ever felt seasick? Only once. We accepted an upgrade to a cabin on a higher deck not realizing that it was right at the front of the ship where if the sea gets choppy the movement of the ship is more noticeable. In future we will always insist on a cabin midship

Passengers joke that by the end of a cruise they'll need a larger size in clothes. Yes, I wouldn't be surprised.

There's a fantastic choice of food, something for everyone – and all included in the price. And if you need something a bit different, perhaps a main course without any sauce or even a gluten-free diet, then all you have to do is ask.

There's so much on offer in the day's programme: it's difficult to choose between deck quoits, the trivia quiz and line dancing. You can even practice your golf on the simulator or play a rubber of bridge. If you feel like taking it easy you can take a dip in the pool, soak in the hot tub or just relax on deck on a sun-bed. Then every evening it's a different show at the theatre, another film in the cinema or, if you prefer, ballroom dancing or disco. All this only minutes away from your cabin...and yet all the time the ship is sailing on to a new and fascinating port of call.

So if, like me, you long to visit faraway places, but need to feel secure and have all the comforts of home, cruising is the holiday for you.

Rosemary Brierley

“Free yourself. Free the planet.”

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If you often feel that trying to find somewhere to dispose of your pouch is ruling your life, you're not alone. However, with new improved Freestyle Flushable this no longer needs to be the case as it simply flushes away.

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Sending goods abroad is always complex - shipping abroad is expensive, adds a considerable delay and there is the issue of the delivery potentially not clearing customs. However, if you are planning to spend a long time overseas we can assist you in many ways. You may be eligible for help locally at your destination and we can help you plan for a problem-free trip by making sure you have all the appliances and accessories you need before you go.

What is World Assist Alliance?

The World Assist Alliance is a programme offered by companies around the world that supports travellers with stoma and continence needs.

It is a group of independent companies that have recognised that when travelling people may need help getting hold of goods or specialist advice, in either an emergency or during a long stay.

How Does World Assist Alliance Work?

Each partner of the network has made a promise to help member travellers when visiting their country in a time of need.

Should an emergency arrive while abroad, the traveller can call their home World Assist Alliance partner who will then contact the World Assist Alliance network on their behalf, and arrange for the necessary goods to be delivered.

Founding member - Fittleworth

Fittleworth is the founding member of this international network of delivery companies just like us across the world, all dedicated to delivering stoma and continence appliances.

Each member has signed up to a promise that should you have any problem while in their country, they will help you out with emergency supplies of appliances and, in most locations, specialist nursing advice too.

By calling Fittleworth you can avoid all the unnecessary complications of dealing with a foreign health system, overcoming language problems in the local pharmacy and explaining your medical condition. The service is free for the supply of goods in emergencies and there is no need to get a prescription, claim on insurance or complete unnecessary forms.

Frequently Asked Questions

How does the system work?

If a Fittleworth customer runs into trouble with their goods abroad, they simply contact us in the UK, letting us know their issue, requirements and location. We then contact our overseas delivery partner in that country and organise a local delivery out to their hotel or accommodation as soon as possible, often the next day. We can also arrange for a local nurse to contact them, should they require nurse assistance or advice.

Which countries are included?

The World Assist Alliance is currently available in the following countries:

- Australia
- Austria
- Belgium,
- France,
- Holland
- New Zealand
- Portugal
- Spain
- Switzerland
- USA and Canada



A service as unique as you are



We have also been able to help customers in Germany and much of Scandinavia and the number of countries where help can be provided is growing, so people should ask us if their particular destination is covered.

Who can use the service?

The World Assist Alliance is only available to Fittleworth Customers who have received three UK orders or more. To register with Fittleworth and for more information please contact one of our dedicated Customer Service Team.

What about cruises?

Travelling by sea should not present as many problems as other forms of travel as ships are more spacious and have more accessible facilities. It is worth contacting the travel company who runs the cruise to find out if they carry spare pouches on board and if they might have room to store any goods that you need to take with you.

It is a good idea to make a note of where the medical room is located when you first board the ship, and how to contact the ship's doctor should you need to.

If you are on a cruise and cannot use any of your pouches for some reason, such as a faulty batch, you can call Fittleworth, letting us know where your next stop will be, and we can see if our contact in that country would be able to deliver some new supplies to where the ship is docked, or an agreed location nearby.

What if I am unable to obtain my usual products?

Some products are more widely available than others and it depends on the country. In the UK we are very lucky with the amount of products available, and often manufacturers will launch new products here first. Therefore sometimes it will not be

possible to find the exact products you use in the country in which you are travelling. However, Fittleworth's dedicated customer service team are able to discuss alternative products with you, and ensure that a suitable alternative can be found.

Do customers have to show any identification when goods are delivered?

Customers do not need to show any identification, but they do need to sign for deliveries to confirm that goods have been delivered to them.

Does Fittleworth give customers a list of contacts before they travel?

We have found that it is best for customers to contact us directly at our UK office, when they have an issue abroad.

From here, we have all your details on our system, including the products you use and can therefore assist with finding alternative products should your usual goods not be available in the country you are travelling in. Fittleworth also has a dedicated member of staff who deals with all World Assist enquiries and has individual contacts within various delivery companies around the world, meaning your problem can be sorted out in the most efficient way possible.



If you have any other questions or would like to know more...

Contact:
Fittleworth
FREEPOST
Hawthorn Road
Littlehampton
West Sussex
BN17 7LT

Freephone
0800 378 846

Online
Email: caring@fittleworth.com
Website: www.fittleworth.com

Editors Comment

If you have used this service or one similar why not tell us about your experiences. You can get in touch via e-mail: editor@colostomyassociation.org.uk or write to:
Colostomy Association
2 London Court East Street
Reading RG1 4 QL

Fittleworth celebrates a silver service

Fittleworth is celebrating its Silver Jubilee as a market leader specialising in the delivery of stoma products.

It was 25 years ago that Alan Seymour started his business from a small garage in the West Sussex village of Fittleworth. Alan saw a need for ostomists to have their appliances cut for them and sent to them directly, and the company grew from there.

Over the years the company has grown hugely, expanding to fourteen Care Centres around the country.

His aim was to deliver stoma goods quickly, discreetly and reliably. Today the company prides itself on knowing that this ethos has not changed. In addition it has been constantly developing new practical and helpful facilities such as its Samples Service and World Assist Alliance – always finding ways to help ostomists live an easier lifestyle.

The 25th year of Fittleworth will be celebrated in a number of ways that reflect how far the business has come, one of which being a more detailed history of its growth in the next issue of the Tidings.

Fittleworth would like to thank the loyal members of the CA who have supported them. As such, the company will be launching its Life Assist initiative which will be an opportunity for you to find out how Fittleworth can help you get the most out of life.

To find out more about Life Assist and how Fittleworth can deliver your stoma products call us free on 0800 378 846 or visit our website:
www.fittleworth.com

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Erectile dysfunction is usually symptomatic of a serious underlying medical condition such as Diabetes or Cardiovascular Disease. It is essential that you seek further assessment from your GP before seeking any treatment for your erection problem.



Celebrating 25 years of delivering an easier lifestyle with

Life Assist

2009 is Fittleworth's 25th year specialising in the delivery of continence and stoma products.

To celebrate we will be launching Life Assist - an opportunity to share all that we have learned over the last 25 years about living an easier lifestyle.

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

These are available free to ostomists. To register for a copy please fill in the form below and return to us at our freepost address.

(Please allow 28 days for delivery)



Freephone 0800 378 846
www.fittleworth.com

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West Sussex
BN17 7LT

Name: _____

Address: _____

Phone no: _____

E mail: _____

Readers' writes

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

**Dear Tidings,
RE: IS ANYONE IRRIGATING WITH A HERNIA?
In answer to EP Southampton**

About a year or so after my AP Resection, my surgeon suggested that I should try irrigating despite having a parastomal hernia, as he felt that it would relieve the pressure on the hernia.

I started and, after having overcome initial minor difficulties, did so successfully for 7 or so years. I stopped only because I had a total colectomy and ileostomy just over a year ago - but that's another story.

My method involved using a SASH belt, obtainable on prescription via the GP or Stoma Nurse. I wore this over the irrigation sleeve adhesive part - so it's important to get a SASH belt with the correct sized hole - and tightened it so as to hold in the hernia. Then followed the usual procedure; dilate the stoma with a gloved (and lubricated) finger; run in, in my case about a litre or a litre and a half of warm water; keep the water there for a while by leaving the cone in place; removed the cone (very carefully!) and whoosh, out it all came. I did not remove the SASH belt until my bowel had emptied. On most occasions I did not need to change the pouch for 24 hours, until the next irrigation session. I irrigated daily in the morning as it took about 45 minutes from beginning to end. Once the water was in and the bulk of the contents of my bowel had emptied into the toilet, I pegged up the sleeve and had breakfast before finishing off and putting on a pouch.

I would recommend irrigation to any colostomist who is able to do it with the agreement of their surgeon or Stoma Nurse as for me it really seemed the closest thing to having a rectum and anus. I only wish I could irrigate now!

**G.P. (Mr)
Newport (South Wales)**

If you want to be involved in the next issue of *Tidings* magazine - simply drop us a line via email: editor@colostomyassociation.org.uk

or write to:

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

Look out for our new Reader Panel Button (opposite) in the next issue to see where readers have been involved.



**Dear Tidings,
RE: IS ANYONE IRRIGATING WITH A HERNIA? -
In answer to EP Southampton**

I had a colostomy performed approximately 20 years ago, as a temporary solution, but it ended up being permanent. I was devastated, and was one of the first at my hospital to go for irrigation. As far as I was concerned it was the best thing since sliced bread. I also put two litres of water through every day which took me fortyfive minutes to an hour, my perfect life once again.

As time went by I also developed a hernia, but I was not going to let this stop me, although I was experiencing many problems, a lot of the irrigation water was not returning, and then it stopped altogether. Hence the warning.

One day I experienced extreme abdo pain actually screaming in pain. I was admitted to hospital and a laparotomy was performed. I did not wake up again for three weeks, to find myself in ITU. I had perforated my large and small bowel in three places, had septicaemia, peritonitis, and was on life support with a tracheotomy also left side weakness, which has left me with brain damage. Apparently the family stayed at the hospital the whole time and was told I had only a 20% survival rate. lucky for me I did survive, but I am left with only half my large bowel and 30cm of small bowel. I am now fed on TPN (total parenteral nutrition) for the past 10 years as I can not absorb enough food to live on. Life has never been the same since, socially not being able to go out for meals with friends and family, as it makes them feel uncomfortable, frequent hospital appointments, planning holidays takes months to arrange, but still I am very grateful to be alive, and live life to the full as far as I can.

The morale of this reply E.P Southampton forget the irrigation. I know stoma bags are not so good, I have a stoma bag again now and if I could have my time again I would have stopped irrigation when I had my problem with irrigation, and I would not be in this position now. What happened to me was my fault entirely, I always thought it can never happen to me.

**G.D
Norfolk**

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Readers' writes

Dear Editor

Response to 'Coping with Chemotherapy, Radiotherapy and a Colostomy'.

I've just read your article 'Coping with Chemotherapy, Radiotherapy and a Colostomy'. I found it very interesting and informative especially with respect to other peoples' experiences. In my case I too was well following Carcinoma of colon with resection in 1994, although I never felt comfortable when sitting.

However the situation became much worse eight years later when I was in constant pain and I was unable to sit down even at home. As you can imagine it greatly affected my social life. As a result I was given medication, attended osteopaths, acupuncture, and lastly to a physiotherapist who suggested that my pain might be psychosomatic. My G.P. was very good and made sure that nothing was missed. She referred me to various consultants, orthopaedic, rheumatology and oncology. I had cat scans and MRIs.

When all else failed I was referred to Pain Management Consultant who immediately knew what was wrong without even examining me. Why didn't the others? In his experience he diagnosed scar tissue from the operation and burning nerve damage from radiotherapy treatment. All in all it has taken me nearly four years to get to this point. Now with extra medication and Lidocaine patches I am able to sit for longer periods so long as I pace myself, by watching T.V. and reading in the lying down.

I do hope that others with similar problems can get the treatment quicker than I did, so they can have a better quality of life.

J.R (Mrs)
Tyne and Wear

Dear Editor Tommee Again

I am a carer for my elderly brother who is a colostomate and who lives in an upstairs flat and which sometimes make the disposal of bags difficult, especially trekking to the bin when its pouring with rain! After seeing an article in your magazine concerning the Tommy Tippee bin, we purchased the same from Mothercare (£9.99). What a difference!!!! I just wish we'd known about this bin before (which would have made life so much easier). There's no more running out in the rain; definitely no smell; and no problem of having to change a bag in the middle of the night and leaving it till morning, or indeed the worry if visitors are staying.



Anybody experiencing difficulties in disposing of their bags should definitely invest... it really is worth its weight in gold and makes life so much easier!!

If, anyone feels they don't wish to invest in the bin, I have also found nappy sacks very useful for disposing of soiled bags, given that they're fragranced and can be bought quite cheaply from any supermarket, and again prevents the worry of any smells emanating from your dustbin.

I hope this is of help to any readers out there experiencing similar disposal problems, and again I just wish we had known about this particular bin right from the beginning which would have made life so much easier!

Good luck to anyone purchasing...one tip...its best to use the 6months+ cartridges for use with the bin – definitely.

D.B

Dear Tidings

Response to Parastomal Hernia

Thank you for your great magazine. In 2001 I had to have a colostomy operation I have developed a large parastomal hernia which my consultant does not want to operate on, as she says it will cause me a lot of problems, as I have no muscles left in my abdominal wall.

The stoma nurses provided me with some support pants which help cosmetically, but I don't care what it looks like it is just so heavy. I was reading the last issue of Tidings and saw an advert for a leakage belt, I telephoned the number given and spoke to the gentleman who designed and makes the belt, I explained I have a large hernia and I am getting a lot of leakage because of this. He said I needed the hernia belt for daytime wear and the leakage belt for night time I had to get a prescription from my doctor and I sent this to him with my measurements and within 5 days of my call I had my two Sash belts. They really are fantastic take away lots of pain and really support me. The gentleman who designed and makes them is a colostomist himself so understood what support was needed. Thank you to him and all of you for producing the magazine.

L.B

Editors Comment

Dear All

Thank you for your letters and emails we welcome them all. Whether you are a new or regular reader of this section you will appreciate the comments and experiences contained within - anyone can contribute and it is essential that you keep your letters and e-mails coming as they give help, support and comfort to all who read them.

We will always do our best to print them. Editing may be required for reasons of clarity or space. In the interests of confidentiality we will publish only your initials, not your full name, unless you give us permission to do so. Yours Ed

Dear Editor

Again I have been engrossed in Tidings, there are topics for all ostomists.

The tips in the last few editions have been very helpful. Regarding hernia's and pancaking, both of which I've experienced with my colostomy. I have put covers over the filter and it has really help solve my ongoing problem.

My stoma is nearly nine years old and was the result of an emergency operation due to a perforated bowel, septicaemia, peritonitis, and MRSA and I was very unwell for a while.

It took me nearly two years to accept my stoma and to thank the surgeons and all involved with the recovery from I.C.U., nurses etc.

What made things worse for me was the fact that I'm unable to deal with the changing of my stoma due to being visually impaired and require my daughter or husband to deal with it, which they do brilliantly.

In the first year following surgery I was admitted to hospital six times with blockages and peristomal hernia repair.

I was told I needed to have a loose output and things improved greatly and up to last March I was coping well. I under went further surgery for two hernias, perforation and adhesions.

The only thing that has been a big issue to me, which I need advice about is this:-

If I wear briefs it stops my stoma working as the output is unable to go into my stoma bag. It leaks round the flange even when I use extensions this causes embarrassment and makes me very wary of going out. The only way its able work properly is when I don't wear my briefs.

I have had holes put in my briefs but I've experienced problems with my stoma protruding out which then causes problems with my hernia.

I was told by the stoma nurse that I cannot try irrigation due to the siting of my stoma, as there wasn't any preparation prior to surgery,

If only I could solve this problem I would have no issues with living with my colostomy.

Should any ostomist be experiencing the same problem - their tips would be gratefully received.

Thank you for a superb magazine which is invaluable to all ostomists.

My very best wishes to all keep up the excellent work you do.

S.R
West Yorkshire

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Dear Nurse

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



Q: *I would like to ask a question re-my stoma, but before I do I will give you a run down on my colostomy. Firstly I will tell you that I am 88 and I am as healthy as a cricket! No aches or pains, and I am not taking any medications.*

I had my operation on 5th November 1991, I had cancer of the bowel and a large portion of my colon removed. Again I am lucky, in that I have never had any trouble with my colostomy. However, during this past year my stoma protrudes 1 1/2 to 2" outside my stomach and when I change my pouch and clean up it takes a while to force the stoma back into my stomach. Sometimes it is as hard as a stone, but after bathing it in hot water it softens up and I can gently ease it back into it's socket. After a while it forces itself out again and remains like that until my next change of pouch. It does not cause any pain and my motions are quite normal. I have a healthy appetite and can eat most foods without any ill effect. I would like to point out that I do not have a hernia. Do you think I should take any action regarding this? Also, do you think a sash belt, or a stoma support hernia belt would be of any use? Your advice would be appreciated

A: This sounds very much like a small stomal prolapse and is nothing to worry about. However it may be uncomfortable and could increase in

size with time. A hernia support belt will not help but it may be worth visiting your stoma care nurse as there is a new belt on the market which has an extra 'flap' to cover the stoma prolapse and help to support it. It is made by a company called Penlan Medical and your stoma care nurse will be able to advise you and order the correct size if needed.

Q: *I have had a colostomy for 15 years and have very sensitive skin which reacts to the adhesive. My skin gets very pink/mauve and it breaks down in places. I have tried barrier cream which helps but my skin never completely recovers. Hae you any other suggestions please.*

A: You say you have tried several different barrier creams without any success. Have you tried other manufacturers pouches as it may be that your skin reacts to a certain pouch only and by changing to an alternative this solves the problem. Alternatively, if you find you react to

lots of different pouches you may find it useful to use 2 different pouches (made by different manufacturers) which you can then alternate. I have several patients who have similar problems and they find by doing this their skin does not react to a specific pouch as they change to an alternative before this happens.

Q: *I had surgery in 2005, rectum sealed off, now I have a colostomy. No problem till yesterday. Had a bowel movement, quite firm but with blood on the outside of stool. Small amount to cover q-tip end. Could it come from my stoma (as I am having movement)? As my stoma steeps blood when I change*
Thanks

A: Blood from the surface of a stoma is not uncommon. However, if you noticed blood on the stool itself when you passed the motion it is advisable to see you GP. He can then refer you back to the hospital for investigations. This will identify any problems and allay any worries you may have.

Q: *I am having a bit of a problem with the skin under the bag. Although I use a glue remover and take the bag off very gently, I saw some blood on a site which, unfortunately, I cannot leave open by cutting away some of the flange. Have you any advice, please?*

I am a paraplegic so I have no feeling and do not know whether there is any pain or not. I do not use any LBF as I found they were just making it more difficult to remove the bag and my skin never seemed any better off than I was before. Normally my skin is quite well behaved and , when I have a poor looking spot, I just treat it with Betnovate-a tip from



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my stoma nurse who has had the inconsideration to retire. I was expecting her to be on call until I passed on to the Great Stoma Clinic in the sky but she made the lame excuse that it was time to retire as she was 60+. Pity, she really was a superb nurse.

A: I am sorry to hear your stoma care nurse retired but I would hope she has a replacement at the hospital that you could contact. Unfortunately sore skin on occasions is not uncommon and although you find that LBF has not worked for you there are lots of skin protection products available to help prevent this. You do not say if this is an area of sore skin or is ulcerated so it may be worth contacting the local stoma care nurse for a review. It may be that if the area is wet and weeping a powder such as Orahesive is needed or a special ring such as a Cohesive Seal or Adapt Ring may help to protect the area whilst it heals. Your local stoma care nurse should be able to advise the best course of treatment for the soreness/ulceration and also get you some samples of other skin protection products to try once the area has healed.

Q: *I am a colostomy patient plus a Registered Nurse. Is their a supplement or vitamin that will help decrease the fluidity of the stool thus making it firmer.*

I think I remember gelatin supplements from a stoma care nurse that helped me originally with my colostomy.

A: For colostomates diet can impact on the consistency of the stool with certain foods containing fibre helping to make the stool firmer. Also certain foods can make the stool more fluid such as citrus fruit and fruit juices. It may be worth keeping a diary to note what foods you eat and the effect they have on your output. Our guts are as different as we are as individuals and therefore foods can affect us in different ways. By keeping a diary you will be able to identify which foods suit you and can then change your diet appropriately. If changing your diet does not help then

medication such as Fibregal may work. If the output is very loose medication such as Loperamide or Codeine can help but they are more likely to cause constipation than Fibregal and should be used with care and supervision from your GP.

Q: *I have had a colostomy since January and at the moment I am secreting a clear bile like liquid from the opening which in turn does not allow my flange and bag to fit properly as it is not adhering because of this problem. Perhaps you could tell me if this secretion is normal and how to deal with it.*

A: You do not say if you had an end or a loop colostomy fashioned. This sounds like a mucous discharge from the stoma which is common from the distal or inactive end of a loop stoma. A natural function of the bowel is to produce mucous as a lubricant for the stool passing through and inactive bowel will still produce this. If the amount is too great it can cause problems with adhesion of the pouch. It may be worth visiting your stoma care nurse for a review. She will be able to tell you if this is mucous from the inactive end or if it is fluid exuded from the stoma itself. She will also be able to check the size of the stoma to ensure the template is fitting correctly as an incorrectly fitting pouch will cause leaks. If necessary she will be able to advise on extra adhesive rings to help with the exudate to cure this problem for you.

Q: *I had an emergency colostomy on 17/12/08 and have seen two surgeons regarding reversing the colostomy. Both agree it is reversible and one is ready to do the reversal now (the original surgeon). The second suggested I wait another month so that the scar tissue could become "more pliable" and he also wants to do a colonoscopy before the reversal but I am quite concerned about a prep for that as I have had them in the past.*

I need to decide who will do the surgery and plan some ASAP. Is there any real advantage to waiting longer for the surgery and is it

common practice to have a colonoscopy before a reversal? Thank you for your help!

A: You do not say whether you had any bowel removed during the surgery last year and whether or not you had the bowel rejoined with the stoma as a diversion to allow healing to occur. If you had a join (anastomosis) then it is common to check that the join has healed prior to reversal. Also you do not state why you had the original operation and again it may be necessary to check the remaining bowel prior to reversal. I would suggest going back to see the surgeon who performed the original operation to discuss your concerns in more detail. He should be able to answer all your questions and help you reach the correct decision for you.

Editors Comment

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

Why not write to us at:-

Colostomy Association
2 London Court
East Street Reading RG1 4QL

or e-mail
cass@colostomyassociation.org.uk

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

Marketplace

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If you have anything to sell, an event to advertise or a message to communicate, you can place a small-ad for as little as £20. Please contact Jane Wood at Head Office on 0118 939 1537 for more details. Advertisements received before 27 February 2009 will be considered for inclusion in the next issue of Tidings.

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The Young IA Sub-Committee bring you the Young IA Weekend 2009
26 – 28 June 2009
YHA National Forest, Derbyshire

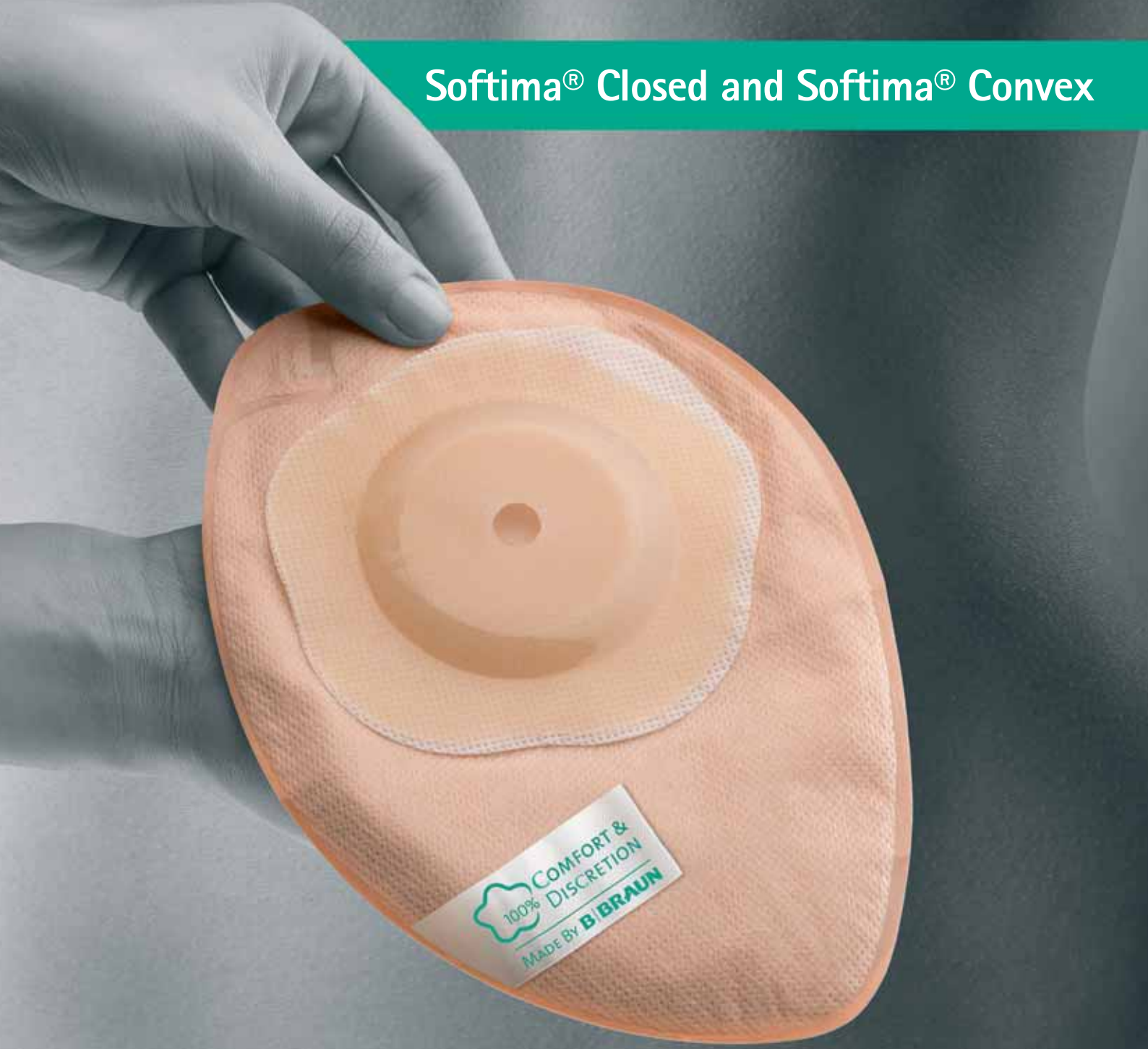
For 2009 Young IA are going "wild". Come along and try out some new activities, or revisit your youth! We'll be "messaging around on the river" in canoes, "reaching for the stars" on the climbing wall, and "enjoying" some fun team based activities.

To book a place or for more information regarding the 2009 Young IA Weekend visit the Young IA website: www.youngia.org.uk or alternatively please contact IA National Office (info@iasupport.org) or 0800 0184 724

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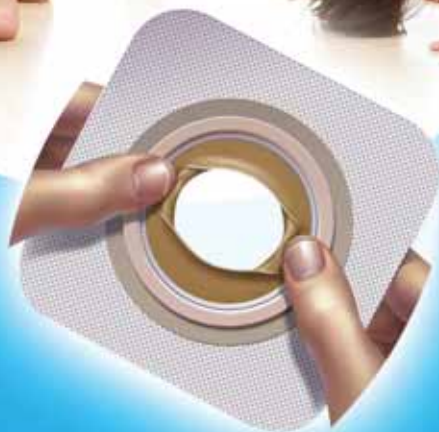


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Scottish Stoma Forum at Scottish Parliament



In 2006, NHS Scotland changed the way in which stoma patients received support, and the way they accessed products. Sponsorship of the stoma care nursing service, which existed in some parts of Scotland, was ended, and all company sponsored stoma care nurses were transferred to the NHS. Pharmacy contractors and dispensing appliance contractors were given equal conditions and contracted to work to new, revised service standards. Assurances were given that the range of appliances would not be reduced, and that NHS Boards in Scotland would provide at least as much choice as was then currently available. Since that time, there has been the introduction of a limited range of products to new patients in secondary care (ie. the hospital setting).

All through the process, representatives from the patient support groups, healthcare professionals (stoma care nurses) and industry have been meeting regularly to monitor the situation and to ensure that the best interests of patients are upheld and that patient choice will be maintained. This has been facilitated through the Patients,

Industry & Professionals (PIPS) Forum Scotland which was re-launched as the Scottish Stoma Forum (SSF). Its first action was to organise an information event on 13th January 2009 at the Scottish Parliament.

The SSF brings together patient representatives, industry, and healthcare professionals with the aim of sustaining high quality products along with a wide range of choice, to help stoma patients achieve the best quality of life. The SSF involves patient representatives from around Scotland, who are able to provide us with the patient experience of stoma care. Healthcare professionals can use the Forum as a way of raising concerns without fear of being singled out. For industry it allows a way for them to better understand the market they serve, developing products that meet the requirements of stoma patients.

The reception at the Scottish Parliament was hosted by Nanette Milne MSP and was attended by Members of the Scottish Parliament (MSPs) involved in healthcare. We have always been encouraged by the support given by the MSPs in Scotland. Every MSP received an

invitation to attend the meeting and they also received a written parliamentary briefing providing an introduction to the SSF. The briefing set out in simple terms the key issues that have faced patients, professionals and industry since the changes in 2006.

The new chairperson of the SSF is Aileen McKinley, a colorectal surgeon at Aberdeen Royal Infirmary. Aileen outlined the objectives of the Forum and offered an open invitation to MSPs to meet with the Forum to discuss the issues further.

This was a positive event where members of the Forum were able to provide information to the politicians and obtain useful advice from the politicians on how to move forward. Through the SSF we will continue to ensure that the interests and experiences of patients are represented.

Article reproduced courtesy of Anne Demick
IA National Secretary
(IA Journal 203)

"My stoma care nurse was brilliant but I still wanted to speak to someone in the same position as myself. If only there was someone that I could speak to with a colostomy"...



Carole Summer talks about becoming a CA volunteer and support group organiser (Southampton Ostomates Support Group)



When I had my colostomy nearly five years ago I asked the staff at the hospital (private) if there was someone that I could speak to who had a colostomy, unfortunately although they tried they could not help. I had not known anyone with a stoma and knew very little about it, the whole future looked very frightening particularly as I was single.

At the time I had not heard about the Colostomy Association and did not know where to turn for help, my stoma care nurse was brilliant but I still wanted to speak to someone in the same position as myself. I heard (cannot remember where) about the then British Colostomy Association and it was so good to read in 'Tidings' about other peoples experiences and all the help and advice that was given. Through the various advertisements I was able to send for samples of different products as my skin was very sensitive to many of the pouches, I was eventually able to find one which suited me.

I read in 'Tidings' that the CA wanted volunteers to help others who were about to have or had recently had surgery for a colostomy, I knew that this was what I wanted to do as this was the one thing that had been lacking during my recovery. With others I attended a training course at the Head office in Reading where everyone was very welcoming and

friendly. To my delight I was accepted as a volunteer and was assured of back up and support from Head Office. I felt rather sorry for the first patient that I visited in hospital as I was so very nervous, but I need not have worried, as she was so pleased to see me looking 'normal' and healthy. I visited her several times in hospital and then at her home, she was always glad to see me. She was the first of many people I visited both in hospital and at home, each one seemed delighted and encouraged by my visit. I realised people just wanted to talk about their experiences and problems to someone in the same situation. The stoma care nurses who are invaluable only have so much time to give, I had time to listen. I read an article in 'Tidings' about stoma support groups but there were none in my area. Although I am by nature a very shy and quiet person I felt that I wanted to set up a group so that more people could enjoy the friendship and support of people who understood their problems.

The first thing I did was to contact my local stoma care nurses to see if they were happy for me to do this, they were more than happy and said they would support me in my venture. My next task was to find a venue that was big enough for us to grow into and easily accessible for people to get to. I am very fortunate in belonging to a wonderful church that does many things for the community and has several groups using their facilities, they agreed that I could have a room on a monthly basis, I was ready to start. How was I going to let people know that I existed? I told some of the people I visited about it and Tidings published a small article about it.

Our first meeting was on March 23rd 2008, it was attended by the senior stoma care nurse and six people with stomas. The meeting went very well thanks to the stoma care nurse as I was very nervous. I remember lots of people wanting to tell of their

experiences, all at the same time! I was worried about the second meeting and Beryl and Ray from the Colostomy Association came along to give me their support, they were great and helped me to relax. Since then the group has grown, we meet every month and have speakers from manufacturers at some meetings and our wonderful stoma care nurses at others.

I have met some wonderful people and made many new friends. There are two men who had their stomas at about the same time and they are able to talk together about their progress, also two admirable, uncomplaining ladies who both have colostomies and urostomies they are able to share experiences. I am very fortunate that I now have a Chairman (lady) and a Treasurer, also a kindly gentleman who always makes the tea, cakes are given by various members voluntarily for which we pay a £1 each, we also have a raffle at some of our meetings and when we have a speaker from one of the manufacturers we ask for a contribution towards the group. One of the manufacturers has kindly offered to pay the Church for our room. Our numbers have grown from six to twenty in just one year, some see the notice in Tidings others are referred by our stoma care nurses and some are people that I have visited in my capacity as a CA volunteer. Some members travel up to 40 miles to get to the group, others live in the village where it is held.

I would like to encourage any of you that have time to spare to consider becoming a volunteer for the Colostomy Association and if there is no support group in your local area to think about setting one up. I would be more than happy to talk to anyone who would like to consider either or both of these ventures.



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

Is there a stoma support group in your region?

There are many stoma support groups throughout the United Kingdom and Ireland, the following pages show stoma support groups listed on our current database by region and by county. As you can see from the list not all counties are covered...



Can you help us to fill in the gaps?

You may be able to find out about stoma support groups from the following sources...

- Try asking your doctor, stoma care nurse or hospital
- Check out information boards at libraries, local councils or community health centres, hospitals
- Search the phone book or other directories
- Search the Internet

Thank you



Scotland

Midlothian:

GOSH

Contact: Alex Topping 01501 772154

Maggie's Edinburgh Timetable

Contact: 0131 5373131

Glasgow:

Fittleworth Support Group

Contact: Maureen (SCN) 0800

7837148

Ayrshire:

North Ayrshire Stoma Support

Contact: Jim 01292 220945

(S.C.A.R)

Contact: Maggie 0781 7736147 or

John 01290 550551

Fife:

Fife Ostomy Support Group

Contact: Ishbel Barr 01592 772200

England



NORTH

Cheshire:

Hand in Hand

Contact: Julie Davis Secretary

Cestrian Support Group

Contact: David Burgham 01244

310461

Warrington Ostomy Support Group

Contact: Jane Shaw 01925 662103

Countess of Chester Hospital

Contact: Julie Clements 01244

365490

Drop in Clinic

Contact: Angela Perks/Deborah

Singleton 01625 661598

Cleveland

Oops Group

Contact: Julie Morrisroe SCN

01287284113

County Durham:

South West Durham Ostomy Group
 Contact: Betty 01388-814535 Brian
 01388 763684

Derbyshire:**Stoma Support Group**

Contact: Anne Wilcox
 01283 214389

Lancashire:

Trafford Bowel Care
 Contact: Jackie Carey Secretary 0161
 7489659 Doreen 0161 9627818 John
 0161 7484655
 Oldham Stoma Support
 Contact: June Wilde 0161 6787086
 Salvation Army - Sr Georges
 Contact: Stella Prince
 01204 413718

Leicestershire:

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

Merseyside:

Olivia Thomas Suite University
 Hospital
 Contact: (Evening) Barbara Percy 0151
 5292842
 I.C.U.P.S
 Contact: Carol Anderson 0151
 3277589
 Liverpool Support Group
 Contact: Barbara Percy 0151 5292842
 (Afternoon)

Northumberland:

Northumberland Cancer Support
 Contact: Pat Fogg 0191 4102679

Teeside:

Bowel Cancer support (Semi Colon)
 Contact: Mr G Dickson 01642 563747

Tyneside:

Gateshead Health NHS trust
 (Stoma drop in clinic)
 Contact: 0191 4878989 ext 2221
 Royal Victoria Infirmary Support Group
 Contact: Gordon Weatherburn 0191
 2341109
 NHS Molineaux Centre
 Contact: Lesley Brown 0191 2195656

Yorkshire:

Airedale Stoma Support
 Contact: Jo McConnell 01535 634815
 Dewsbury & District Ostomy
 Contact: Janet/Eileen 0844 8118110
 Scarborough Stoma Support Group
 Contact: Sister Jean Campbell 01723
 342388

Rotherham Ostomates Caring Support

Contact: Karen Kilford 078880 575758
 CROPS (Colo-rectal ostomy & internal
 pouch support)
 Contact: Gloria 0114 2879503

Isle of Man:

Stoma Support Group
 Contact: Carole 01624 650212
 Optimistics
 Contact: Stoma Nurse Lynne Webb
 SCN 01983 534009

**Nottinghamshire:**

Nottingham Colostomy, Ileostomy &
 Urostomy support group
 Contact: Rosemary Brierley 0115
 9826691
 Mansfield Stoma
 Contact: Gerry Marshall 07794 159267

Staffordshire:

Outlook
 Contact: Ernie Hulme 01782 324441
 Joan 01782 710828

West Midlands:

Colostomy Group
 Contact: Pat Keane 0121 4242730

**Lincolnshire:**

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

Norfolk:

Stars
 Contact: Anne Brown 01603 661751

Suffolk:

James Pagett Ostomy Support Group
 Contact: Sandra Hutchings 01502
 585955
 East Suffolk Ostomy Group
 Contact: Marion Fisher 01473 311204
 West Suffolk Support group
 Contact: CA for details

**Bedfordshire:**

Saturday Social Club
 Contact: CA for details

Berkshire:

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

Buckinghamshire

Milton Keynes Stoma Association
 Contact: Bruce Pollard 01908 582563

Essex:

M.E.S.S (Mid Essex Stoma Support)
 Contact: Clive Blanchard 01245
 468750 Jeanette Johnson 01376
 511862
 North Essex Stoma Support
 Contact: Mr W Hatch 01255 503688
 Brian Waller Secretary 01206 540449
 Redbridge Ostomists Club
 Contact: Stoma Nurses: Chris/Lisa
 0208 9708321
 South Essex Young Ostomy Group
 Contact: Paul Gray 01708 501268
 Optimistic Ostomates
 Contact: Janet 01702 385510 Angela
 01702 385509
 STEPS
 Contact: TBA

Hampshire:

Southampton Support Group
 Contact: Carol Summer 02380 446779

Hertfordshire:

Colonise
 Contact: CA for details
 Stoma Fellowship
 Contact: Karen/Mandy 01438 781133

Kent:

Dover & District Stoma Support
 Contact: Marie Culleton SCN
 01233 616646

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SUPPORT GROUPS IN YOUR REGION?

Ashford Stoma Support
Contact: Chairwoman - Ursula Naish
01233 640863

London:

Whipps Cross University Hospital
Contact: Christina 0208 5395522
Ealing Ostomy Support Group
Contact: CA for details
South Woodford Ostomy Support
Group
Contact: CA for details

Middlesex:

Inside Out
Contact: Bob (chairman) 0208
4284242 Sarah Varma 020 82354110
Semi-Colon Club
Contact: 01895 179391

Oxfordshire:

Oxfordshire Ostomy Fellowship
Ernest Draper 01865 391257

Surrey:

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

Sussex:

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



Avon:

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

Cornwall:

Optimists
Contact: Sue Hatton 01326 340058

Devon:

Devon IA
Contact: Margaret Bond 01392 447374

Dorset:

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

Wiltshire:

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



Wales

Blaenau Gwent Self Help
Contact: Marina Heal 01495 310686
(after 6pm)
Swansea Ostomy Self Help Group
Contact: Glynis Jenkins 01792 418245
Wrexham Ostomy Friendship Group
Contact: CA for details



Northern Ireland

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

Eire



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

Editors Comment

If we can identify other support groups we will be able to help more people 'Living with a Colostomy' and in doing so we will increase awareness of the Association

Here's how you can get in touch via e-mail:
editor@colostomyassociation.org.uk

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



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...



Help us to raise funds so that we can raise our game...

The fund target is £10,000

It sounds like a great deal of money doesn't it. But with this amount we can achieve a great deal - and we will spend it wisely...

The following is a list of what we would like to be able to do with the fund...



• **Publicity Materials**

The Colostomy Association needs to produce new publicity materials. These will be used to promote the work of the charity to health care professionals, hand picked companies and organisations.

With this information we will be able to raise our profile as a charity and send out our message to others.

• **Volunteer Support Materials**

Our volunteers need support so that they can continue to do their good work - we need to provide the tools. A volunteer toolkit to encourage new volunteers, training materials and fundraising goods.

• **Patient and Health Care professionals literature**

There is much to say here - we need to continue to update and produce new literature to address requests. We also need to be innovative - and use new technologies to get our message across. Produce video clips for our website and CD-Rom presentations.

• **Computers and software**

In order for the staff to keep a breast of the demands of a very busy Head Office. The staff need to be able to work smarter. Their computer equipment needs updating as does their software. They need new and different software packages so that they can create communication pieces such as newsletters and factsheets in-house.

**Please help if you can
Thank you**

• **Food for Fund(ds)**

This is a simple fundraising exercise, we hope most of you will take part.

The object is to invite several of your friends and family to your home or venue and give them something to eat and drink. This can be done by a single person or as a group and can be as easy or complicated as you like. The point is that you all have fun doing it.

You charge them whatever you feel is appropriate for what you are providing, subtract your expenses and send the balance to the Colostomy Association thus raising much needed funds for the association.

There are a huge number of ideas but here are just a few to give you food for thought!

- Tea and toast after the school run
- Morning coffee
- Brunch
- Lunch
- Afternoon tea
- After work drinks and nibbles
- Barbeque and beer
- A picnic of any kind
- A buffet
- A dinner party

The list is endless and you will no doubt come up with ideas of your own.

The event can be held at any time between now and Christmas although we do ask that any funds raised are sent to us before 31st December 2009.

Please take photographs of your event and send them to us. We will be able to publish some in Tidings and also give you an update in the Summer, Autumn and Winter editions of the magazine so you know how well YOU have all done.

Enjoy and thanks

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Prescription appliances will arrive discreetly and efficiently at your home, place of work or any other chosen address

We can cut personal templates accurately from both pouches and flanges with our **COMPUTERISED CUTTING MACHINE**.

So you can DEPEND on us to give the most accurate machine cut available

Our Customer Service is recognised internationally guaranteeing our Quality Service.

So you not only experience EFFORTLESS ORDERING but you also have the REASSURANCE of our European stamp of approval



WHY NOT CALL US NOW!!!

0800 220 300 OstoMART_{Ltd}

WE NOW OFFER WET WIPES!

OstoZyme

Odour Neutralising Pouch Lubricant



- Kills odour in the pouch
- Prevents 'pancaking'
- Reduces static
- Aids pouch emptying
- Reduces noise

Dual action **OstoZyme** lubricates the inside of the pouch and actively destroys any odour at source.

OstoZyme contains powerful odour neutralisers - effectively eliminating any embarrassing smells.

OstoZyme Multi pump delivers 8mls every time, for effective use!

OstoZyme is so easy to use.

OstoZyme is water based and does not stain. Specially designed sachets help prevent accidental spillage.

OstoZyme works. Why not try it for yourself.

0800 220 300

OstoMART_{Ltd}

Drug Tariff Listed

Description: OstoZyme - Odour Neutralising Pouch Lubricant

Product Code: TCB3 Quantity: Box 30x8ml Sachets
Product Code: TCB6 Quantity: Bottle of 300ml

UPFRONT

About Stoma Care Open Days... Open days give ostomates the opportunity to meet and share experiences with other ostomates. Many people attend with friends and family and it can be a very sociable event.

Open Days are organised by stoma care nurses working within the NHS, stoma care manufacturers and/or suppliers. These events offer you the opportunity to chat to stoma care nurses about any problems you may be having, speak to company representatives who may order free samples for you, or meet up with CA volunteers who have everyday experience of living with a stoma. The IA or UA may also be represented.

As an added bonus you may receive free entry into a museum or garden, depending on where the open day is being held.

List of forthcoming Open Days:

Date: 14/04/09

Venue: Carlton Park Hotel Moorgate Rd, Rotherham

Time: 10.30-2.30

Rotherham General Hospital patient stoma care open day, Raffle in aid of Bowel Cancer UK

Contact: Liz Cooper 01709 307154

Date: 15/04/09

Venue: Freemasons Hall Plough Lane, Christleton Chester

Time: 1.30-5.30

Countess of Chester Hospital stoma care open day

Contact:

Stoma Team 01244 365490

Date: 24/04/09

Venue: The Winding Wheel Holwyell St, Chesterfield

Time: 10.00-2.00

Chesterfield and North Derbyshire Royal Hospital annual open day

Contact:

Steve Crane stephenacrane@jyahoo.co.uk

Date: 25/04/09

Venue: John Radcliffe Hospital Academic Street Foyer Level 3

Time: 10.00-2.00

Oxford Radcliffe Hospitals 2009 Stomatherapy Patient open day

Contact: Colorectal.nursing@orh.nhs.uk

Date: 28/04/09

Venue: Smiddy Room Washington Central Hotel, Workington

Time: 10.00-12.30

CliniMed meeting

Contact: CliniMed 01628 850100

Date: 29/04/09

Venue: Upper Room

The Crossing at St Pauls, Darwell St, Walsall

Time: 12.00-4.00

Walsall Hospitals bowel awareness open day

Contact: Manor Hospital 01922 721172

Date: 9/05/09

Venue: East Surrey Hospital, Redhill

Time: 10.00-1.00

East Surrey Hospital

Contact: Julie Lawes 01737 768511

Date: 13/05/09

Venue: Lord Hill Hotel, Shrewsbury

Time: 12.00-4.00

Shrewsbury and Telford Hospitals Open Day for Stoma Patients

Contact: Royal Shrewsbury Hospital 01743 261144

Date: 20/05/09

Venue: The Guildhall, Market Square, Salisbury

Time: 2.00-5.00

Salisbury District Hospital Stoma care open day

Contact: Stoma Care Dept 01722 336262

Date: 28/05/09

Venue: London Zoo Awaiting details

Date: 13/06/09

Venue: Shiraz Mirza community Hall, Kingston upon Thames

Time: 10.00-2.00

Kingston Hospital stoma care open day
Contact: Kingston Hospital 020 8546 7711

The annual Opus Healthcare Bursary, a research grant of £5,000...



has been awarded to Lesley Law, Heather Dennis and Caroline Rudonni the Stoma Care Nurses at St. George's Hospital, London. The aim of their research is to look at the use of accessory products in Stoma Care, and identify whether there is any consensus of opinion regarding their use.

Index: A-Z of Advertisers

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iMedicare

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Linda Butler

01205 723327

OakMed

0800 592786

Opus

0800 4587605

Ostomart

0800 220300

Peak Medical

0800 6520424

Pelican

0800 0527471

Salts

0800 626388

Sash

0800 3893111

UCI Healthcare

0800 731 4376

White Rose Collection

01202 854634

Helpful Groups & Organisations

Other Ostomy Support Associations...

- IA The Ileostomy and Internal Pouch Support Group
Freephone: 0800 0184 724
www.iasupport.org

- UA Urostomy Association
Tel: 01889 563191
www.urostomyassociation.org.uk

- IOA International Ostomy Association
www.ostomyinternational.org

- Gay Ostomates
Tel: 0844 414 2356
e-mail info@gayostomates.org
www.gayostomates.org

Support organisations for medical conditions...

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

- Cancerbackup
Freephone: 0808 800 1234
www.cancerbackup.org.uk

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

- National Association for Colitis and Crohn's disease
Tel: 0845 130 2233
www.nacc.org.uk

- The Gut Trust
(Irritable bowel syndrome)
Tel: 0114 272 3253
www.theguttrust.org

- Incontact
(Incontinence & Diverticular disease)
Tel: 01536 533233
Web: www.incontact.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 7,000 locked toilets around the UK. Some local councils will provide this key free, or for a small charge.

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

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

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