Autumn 2009 | Issue 15

colostomy association

Tidings

Dedicated to Colostomates their Families and their Carers

inside...

Open Door
a new dimension
in my life...

Ernie Hulme
CA Trustee and
volunteer talks about
the key role
of the volunteer

Irrigation
and you...

Reaching Out
& building
awareness

CA Open Day
Swansea 2009

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welcome to AUTUMN

The Colostomy Association goes to WCET UK 2009

From left to right: Sue Hatton Executive Trustee, Monty Taylor Chairman, Jane Wood Editor of Tidings and Richard Bray General Manager

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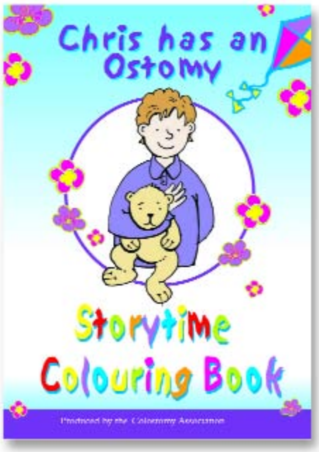

Chris has an Ostomy...
Pelican Healthcare have kindly offered to sponsor the reprinting of this booklet available soon from Head Office

Phew! What a few months it has been since the last Tidings and what a year for the Association, as I am sure you will gather when you read Sue's CA News on pages 8 and 9.

In mid-September we launched our first Patient Open Day - a pilot for future events. The theme was reaching out, building awareness and moving forward. The event took place at The Liberty Stadium, Swansea and was a resounding success. You can read all about it on the centre pages of this issue.

The CA was lucky enough to be sponsored by CliniMed to attend the WCET UK Conference held at the Ricoh Arena in Coventry at the end of September. Our grateful thanks to Maureen Kelly-Smith, Securicare Medical - Nurse Careline/PR Manager, Phillip Allmark, Managing Director, CliniMed and Sean Farbrother, Managing Director, Welland Medical for looking after us so well. Four delegates from the CA attended (see pages 23 and 24). It was a privilege to be asked and I learned so much. I didn't want it to end, so many interesting people from the world of stoma care, talking with such enthusiasm. The discussions covered a plethora of subjects including how to improve patient services, how to identify and solve problems within stoma care but above all how to provide quality of care for patients. I wish I could have captured the whole event on video so that I could play it back to you - maybe next time!

World Ostomy Day followed WCET UK and took place on 3rd October 2009. A big thank you to all our volunteers who attended the events across the UK and to those of you who sent donations. Three years until the next one - I expect that will come around sooner than we think!

I have had fantastic feedback from Christine Hyde - do you remember her from Open Door in the last issue? Tidings visited and interviewed Christine at the Hillingdon Hospital earlier this year. I saw Christine at WCET UK and she told me that she had been contacted by so many people it was amazing. She even said that her son had read the article and now has a better understanding of her work. Christine is keen to do more with Tidings so watch this space.

In this issue 'Open Door' features our very own Ernie Hulme - CA Trustee and Volunteer - Tidings asked Ernie how he became a volunteer and asks, can a volunteer really make a difference within the hospital?

Thank you to all who wrote in or emailed, it is always great to hear your news, stories or receive your queries. Please keep them coming - the more the better!

This time we have an article about stoma care in Australia from Diana Hayes R.N. Master of Advanced Nursing Practice (University of Melbourne) Clinical Nurse Consultant /Stomal Therapy (Credentialled) Western Health, Melbourne, Australia. Tidings welcomes articles from around the UK and the World, it is always interesting to read what's happening elsewhere! It's a small world but I have discovered through working as editor of Tidings that it is certainly one with a big heart.

As always I would like to encourage you to get involved with Tidings - YOU make it what it is - YOUR magazine!

Jane

Email:
editor@colostomyassociation.org.uk

Readers' Panel - Any reader who succeeds in having an article, top tip or particular topic featured in Tidings will see this acknowledgement.

Reader PANEL contributor

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

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

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Editorial Submissions:
We welcome your contributions to Tidings - if you have a story, article or letter that you would like featured in the magazine we would like to hear from YOU!

If you have an idea for an article and would like to discuss this with the Editor or would like help writing your

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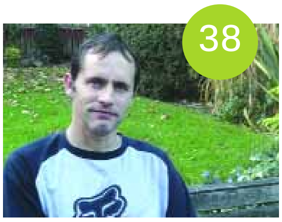
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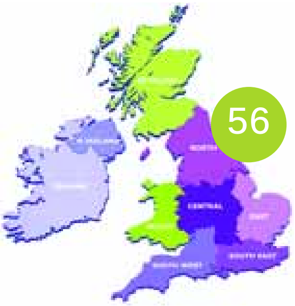
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About...
the Colostomy Association

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

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

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Helpline: 0800 328 4257

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Tidings Magazine Winter Edition advert booking by 21 November copy by 28 November publication January 2010

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

We will always do our best to include your contributions in the next issue of Tidings or will hold them back for a future issue. When submitting your information don't forget to supply your name, address, phone number and e-mail address if you have one.

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

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

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- Images compressed in JPEG format.
- For scanned images please set at 300 ppi in RGB mode and scan original @100%.

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

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BCA10/09

Reaching out...building awareness moving the CA forward

At the beginning of the year, the Trustees of the CA set themselves goals, as all good Trustees do! These goals were quite ambitious and as we near the end of the year I feel quite confident that we have been very successful in crossing off a good number of them!

Our President Professor Bill Heald has made contact with the President of the Association of Coloprotology of Great Britain and Ireland, Mr Najib Haboubi, on our behalf to forge alliances. To our delight Professor Bill has agreed to give a lecture at the Royal Society of Medicine, Wimpole Street, London in 2010. The lecture will be entitled 'Living with a Colostomy', he will also be busy again later in the year giving a presentation about Irrigation at the WCET UK Conference 2010. It is so wonderful that this eminent and very highly sought after Surgical Director of the Pelican Cancer Foundation is determined to raise the profile of the CA within the echelons of the medical world.

Our main activity this year has been to raise awareness about the work of the Colostomy Association.

there are reportedly 100,000 ostomates in the UK

Who ARE we...

What WE do...

Listen&Reassure
Empathise&Support
Understand&Help
Discuss&Refer
Encourage&Motivate

pass on our knowledge, expertise and 'real life' experiences to

ALL who are... living with a colostomy

www.colostomyassociation.org.uk

The above awareness literature was written jointly by Sue Hatton and Jane Wood - production was kindly sponsored by Coloplast. Copies can be obtained from CA head office.

It was decided early in the year to reach out to people 'living with a colostomy' and to professionals working in the field of stoma care.

We did this by identifying, planning and attending relevant events that would give us access to those who we felt needed to know more about our work. The Association of Coloproctology of Great Britain and Ireland (ACPGBI) Annual Conference 2009 was one such event. Here we met surgeons from all over the country and some from as far away as Australia. There were also oncologists, pathologists, radiologists and specialist nurses working in essential care and management roles. For this event we designed much needed awareness literature and exhibition displays.

About ... The Association of Coloproctology of Great Britain and Ireland is a professional society (ACPGBI) representing more than 1000 Colon and Rectal specialists dedicated to advancing and promoting the science and practice of the treatment of patients with diseases and disorders affecting the colon, rectum, and anus. It is also known as The Association of Bowel Specialists.

Just recently, the fab four myself, Monty Taylor, Richard Bray and Jane Wood attended WCET UK 2009. By attending events such as these we hope to ensure that stoma care professionals have an increased knowledge of the work of the Colostomy Association, why we exist and what we as an Association have to offer – which we all know is a great deal!

Agenda

Open Day 2009
Colostomy Association

Reaching out
Building awareness
Moving forward

Venue
The Liberty Stadium
Swansea Suite1 Level 2
Swansea Wales

Date: 10th September 2009
Time: 12:30pm - 7-30pm

For those of us 'living with a colostomy' we ambitiously decided to take on a patient 'Open Day' in preference to an Annual Conference – again the idea here was to reach out to people in areas of the country that are perhaps less well supported. The 'Open Day' held in mid-September at The Liberty Stadium, Swansea was a great success. The day was certainly of benefit to one particular lady who attended. Invited by a member of staff working at the Stadium – Margaret Thomas had recently had an emergency operation resulting in a colostomy – she thought she was all alone – her son brought her to the 'Open Day' and she was delighted to meet fellow colostomates. She went away happy in the knowledge that she could call on the CA for support and reassurance.

I am particularly delighted to announce that we will be organising another 'Open Day' in the early part of 2010. We have identified the West Country as our next port of call, so watch this space!

It has been a year of change and growth again for the CA. We have seen old friends namely Ray and Beryl Goddard move on to pastures new and I can report that they are happily enjoying a well-deserved retirement.

Monty Taylor is cracking on with his role as Chairman, having seen his eldest daughter married in fine style and moving house, all of 100yds! Monty has represented the CA at various events this year including

National Voices, the Great Comeback Awards and is taking on the PIPs forum - a partnership between Patient Groups, Industry and Professional Groups involved in Stoma care. It is a sub group of the BHTA officially launched in 2001 to address issues and challenges for patients, professionals and industry working in stoma care. (Patient, Industry and Professionals).

Ernie Hulme continues his excellent work at the University Hospital of North Staffordshire NHS Trust. He has also been involved with building the CA training programmes along with Bob Buckley and Jean Scott. Robin Mills and Marilyn Beynon continue to be stalwart supporters of the CA and both attended the Open Day at Swansea, Marilyn's home territory. New to the CA Board of Trustees are two welcome additions. We are proud to have Jackie Dudley back with us. Jackie rejoins as a Trustee having had a break for a few years. She is taking on the role of Volunteer Co-ordinator, we have admitted to failing in this aspect, but Jackie's huge energies will gear us up and ensure that we don't lose our very valued volunteer network. Jackie is also on the Tidings editorial team and brings with her valuable patient insight, she also runs two of her own support groups.

Sister Ann Leppington-Clarke was invited to join the board of Trustees. Ann has been a member of the Pelican Board since its inception in 2000. She was appointed Stoma Care Nurse specialist and Endoscopy Unit sister at Basingstoke Hospital in 1981 and started the colonoscopy service. She has worked in colorectal care with Prof Bill Heald and the colorectal team for 26 years. She retired from the NHS in 2003 and presently works with the team as Colorectal Nurse specialist at The Hampshire Clinic where she counsels and teaches patients and their carers about stoma care and colorectal cancer.

We have also seen Richard Bray pass his 3-month point, unscathed! He hasn't stopped and has been brilliant in pulling together policies and working hard on a Strategic plan to form the basis of the future development the CA. He has been ably assisted in this task by a great pal of mine Mary Thomas, who having retired from a post as Head of Internal Audit for a Government Department, was coerced by me, to volunteer her skills as a risk assessor to formulate this document for us. Mary and I joined the Army 40 years ago this September as cadets! Mary joined us at Swansea to see what we were all about. She, Gill and Jo from the CA office were such a brilliant team on the welcome desk at the Liberty stadium.

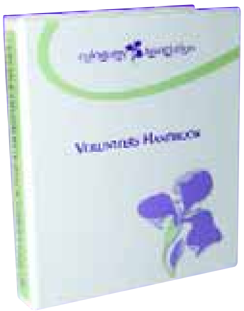
Jane Wood is continuing her work as editor of Tidings and is constantly pushing the boundaries of continual development of the magazine. She also took a leading role in the organisation and management of the Swansea Open Day Event. She continues to support me in my role of raising awareness of the work of the Association and I am sure we will have many more adventures together!

Gill and Jo have worked so hard through this year, seen a lot of changes and stuck with us! Well done you gorgeous girls!! Also to the local Reading volunteers, Jackie, Claire, Heather, Colin and Margaret who regularly assist with anything and everything that goes on at the busy CA head office.

Our volunteers have been working diligently too. Special mention should go to Tom Reid who has attended many Open Days this year. We do need more volunteers in Scotland. Where are you all! Thank you to those who attended the World Ostomy Day 2009 events. You are stars!

As promised in the last issue of Tidings here is an update from CA volunteer Bob Buckley about our volunteer training programme.

In September the training team met at Salts Healthcare in Birmingham to review all feedback from previous courses and to make the necessary changes to ensure the training satisfies our "customers", i.e. volunteers. They also defined the training strategy for 2010.



We are currently working on a Volunteers Handbook which will be rolled out shortly.

In November two courses will be run, very kindly hosted by Coloplast at their Peterborough site, these will be, an "Introduction day" for potential volunteers and another "Telephone Helpline" course. Looking forward to 2010 a new course, "Home and Hospital visiting" will be piloted during the first quarter. If you are a volunteer interested in attending these courses please contact the CA at the Reading HQ.

Through the continued generosity of CliniMed we have been gifted a sponsored stoma nurse, Amanda Gunning will work with us over the coming year to help with training, reviewing and updating our literature and giving professional advice in response to our Helpline calls. Amanda is so enthusiastic and full of ideas we are going to have to gallop to keep up with her! So you see we have a lot of extra hands!

I would like to take this opportunity to say a 'big thank' you to all the companies who have supported the CA this year. Many through continued support of Tidings magazine, which we know from our feedback, means so much its readers, me being one of them! With this support the CA has been able to move forward. You are all very generously helping us to continue to support and reassure all ostomates. It has been great when a company has asked us to produce a wish list and then met one or more of our dreams!

For the next few months I am going to be very busy, as I have to put my Granny apron on! My two eldest daughters are expecting their second babies in October and December! My husband Neil and I hope to have four grandchildren (all aged under 25 months) by Christmas! I'm exhausted at the thought of it! So please forgive me in advance if my next CA news isn't as CA focused as this one!

Sue

Sue Hatton
Executive Trustee
Colostomy Association

A new dimension in my life...

Ernie Hulme - Trustee and Volunteer

talks about the key role of the volunteer in the hospital and community

Tidings asks can a volunteer really make a difference to both patients and medical professionals by working alongside staff within a busy Stoma Care Department of a NHS Hospital Trust

Ernie pictured right with Sister Hillary Feeney from Surgical Ward 108 where most if not all of the stoma patients are looked after.

Q1: Would you tell Tidings a little about yourself...

I'm 59 this coming January. Four years ago I took the opportunity to retire from the family travel and private hire business; the decision was almost made for me due to a health problem unrelated to my stoma. I first met my wife, Carol, who still runs the travel business, when I was a part-time, teenage disk jockey at the then Crystal Ballroom in Newcastle, Staffs just over the border from Stoke on Trent. I hung up my fur coats, rose tinted glasses and bell bottom jeans in 1973 when I got married wearing platform shoes and Cossack hair lacquer; that was 37 years ago this coming February. How time flies when you are enjoying yourself.

We have been blessed with three children: Andrew 33, a teacher, Richard 31 who lives and runs a business in Ireland and my daughter Danielle 24, a full time Mum to my lovely granddaughter Abigail age 4. Richard and wife Janet (in Ireland) are about to present us with our second grandchild around Christmas. The bungalow we have always lived in was bought almost twelve months before we got married early in 1972, that's almost 38 years ago, for the princely sum of £4,170

Q2: Can you tell us how you first got involved with the charity?

About twelve months after my surgery and treatment for bowel cancer had finished I was asked by the specialist nursing team if I would visit a newly diagnosed patient a short distance from where I live. I made contact, went to his home, the patient his wife and myself, sat drinking tea and talking for a couple of hours. I told him of my treatment and surgery - “cancer journey” as it is now referred to - and they asked a great many questions to do with lifestyle, work, relationships and my personal feelings on having to live with a stoma.

I remember tears and tissues, a number of thoughtful silences and searching, personal questions that were answered without a hint of embarrassment. I also found out a lot about myself as we sat talking. The visit ended on a positive note with a healthy dose of laughter. It was such a memorable visit as this was the first time I had looked in on cancer as an outsider and seen how this disease affects the family not just the patient – back then I remember feeling that us patients have the disease and our loved ones have the symptoms. It made sense to me then and it still does today and anyone experiencing the trauma of a life-threatening illness as a patient or through the eyes of a carer will understand.

Q3: How, why and when did you become a volunteer for the BCA/CA?

Looking back I suppose I was volunteered! On leaving the hospital after my last procedure I remember saying to my Stoma care nurse, ‘If I can do anything for you – give me a call.’ I got the call! The stoma care team at the University Hospital North Staffs are and always have been very forward looking, pro-active and understanding of the clinical and psychological needs of their patients. So back in 1996 when I was first diagnosed they offered me a very comprehensive package of care. Over the years they have honed and adapted their skills as new initiatives and treatment plans have been implemented all the time incorporating the services of volunteers to compliment their work and enhance a patient’s recovery and long term rehabilitation. So actually the specialist nursing team were aware of the support available from the old BCA as it was then and along with the Ileostomy and Urostomy Associations and their network of local volunteers the nursing team quite rightly looked to identify suitable new recruits from their own patients that they felt they could work with and who could continue this aspect of their service.

Pictured right also from Surgical Ward 108 is Staff Nurse Dorothy Munyani

Before becoming a “BCA man” I relied on Macmillan, initially for support, then for my education and frequently used their vast range of information to give to newly diagnosed patients. I still support this remarkable charity at every opportunity.

Like a great many patients having major surgery you feel you want to pay back in some way or say “Thank you”. This was my way of paying back and saying thank you all in one.
I became a volunteer for the BCA in 1997, an Area Organiser in 1998 and in 1999 I was presented with an engraved watch for being the Area Organiser of the year.

When the CA was formed I became one of the first Directors and Founding Trustees.

Editors Comment

A big thank you to Ernie Hulme for opening the door to Tidings, for giving up his time and for sharing his story with us. Special thanks goes to all mentioned in this article and the University Hospital of North Staffordshire NHS Trust

Q4: What did you hope to achieve by becoming a volunteer?

A number of things: I very nearly became a statistic due to ignorance of the disease so I wanted to raise awareness of this very treatable cancer and if like me having a stoma became a necessary part of the treatment I wanted to tell people that life with a stoma was in fact not at all bad.

When you hear some of the jokes and comments made about stomas or listen to stories about embarrassing situations that befall us “pouch people” you begin to realise that there is an enormous amount of ignorance out there that unfortunately it is not restricted to the man or woman on the street.

From the small employer to Local government bodies, from providers in the leisure industry swimming pools and fitness suites to those that provide education on a grand scale you will find a high level of ignorance that usually leads to a form of victimisation at its least a very embarrassing situation for some poor pouch wearer. So! A great achievement on my part would be to make people more aware, more informed and educated in mysteries of altered anatomy and the wearing of a pouch.

I gained an enormous amount of confidence in the early stages of my rehabilitation from ordinary people: volunteers who had experienced cancer or living with a stoma, a neighbour who one day dropped into the conversation the fact that he had a colostomy. Communication works in both directions, not only do we give something when we share with someone, we receive as well and providing support to a new found friend especially when you get that magical “Thank you” is very rewarding. For me at least I found a completely new dimension to my life. This involved returning to the

> “Communication works in both directions, not only do we give something when we share with someone, we receive as well and providing support to a newfound friend especially when you get that magical “Thank you”, is very rewarding.”

education system - something I was desperate to leave many years earlier - to attend courses on counselling skills, attend workshops and study days on the many aspects of providing support: how to cope with the various phases of cancer from the shock of initial diagnosis to palliative care. Over the years with each new package of information and shared experience you become more aware of your own personal abilities and more importantly your limitations.

Q5: What areas does your voluntary work cover?

I visit people pre and post op, in the hospital and the home if required. My specialist subject is of course my stoma and experiences of having had cancer so almost all of my work for the C.A. is related to this.

Q6: Where has your voluntary work taken you?

All across the UK and Ireland to many different hospitals, open days and conference venues. For the past few years I, along with other patient volunteers, take ourselves to an unusual venue where we find ourselves lying on an examination table in the University Hospitals Clinical Education Centre. Here we are examined by the next generation of doctors as we help out with the Objective Structured Clinical Examinations for Keele Undergraduate Medical School. Their stoma knowledge is really very good but as I use a Conseal plug to manage my stoma most of the time they are never too sure about what lies beneath!

Pictured above is the Clinical Education Centre

Some of my most memorable trips have come from visiting the homes of new found friends in my extended patch which stretches from mid Wales over to Staffordshire Moorlands /Derbyshire borders. However, sitting in the top five of my most memorable home visits was a Tuesday evening last November when I walked through the main gates of a very special home, that being Buckingham Palace, to attend an evening reception where I was introduced to the Queen. Fantastic. I still have to pinch myself.

Q7: Can you tell us more about what you do within the hospital?

I start my visiting week by contacting the Bowel Care Nursing Team for a list of referrals. This may sound simple but as the team spend almost all of their time with patients either on the hospital wards, in nurse led and consultant clinics or in the community at the patient’s home, finding a time to suit us both can sometimes be difficult. To protect a patient’s confidentiality messages, e-mails and answer phones are never used.

From the list of referrals I will pass on the names of patients that are known to have a specific stoma type requiring a matched visitor for example a patient having a urinary tract diversion (Urostomy) will be seen by a Urostomy Association volunteer. A patient known to have an Ileostomy or having an internal pouch formation will be seen by an Ileostomy Association volunteer. All the volunteers belong to the local support group, Outlook, as well as their National Support Associations. The visiting teams quite often have information about other support services and pathways such as the Cancer Information Centre, Benefit Help Lines, Macmillan, Disability Solutions etc.

The volunteers are all trained members of their National Association but all work under the guidance and supervision of the Specialist Bowel Care Nursing Team. As I enter a ward my first job is to make myself known to the nurse in charge - not too difficult when you stand six feet tall, weigh the same as a small family car and have a hairy face! The fact that I have been involved with visiting for many years and that I may quite possibly be instantly recognisable makes little difference, I am entering the nurse’s domain and must seek their approval. Most of the time even though they are stretched to the limit one of the staff nurses will take pity on me and ask ‘Who have you come to see, Ernie?’ For me this is great as I can get a clearer picture of the patient, their demeanour and any specific needs. A lot of the time it helps to put a stoma type to the name on my referral list, so again I can call on a matched visitor if required.

Nearly all of the patients are aware of the visiting service as it is part of the comprehensive package offered by the Bowel Care Team but I always introduce myself and explain my position to the patient. So within the hospital I coordinate the visiting teams as well as providing friendship, support, experienced-based information and advice to new and not so new stoma patients, their families and carers.

Q8: Do you work alongside medical professionals, if so at what level?

I suppose the answer to this is yes! The consultants and doctors like our specialist nursing team are very generous with their comments about the support group members often referring to them as the "true experts of living with a stoma" which has a very positive effect on how we feel and perceive our role as visitors. Quite often we are asked if we would see a particular patient with a specific question, that as patients ourselves we would be able to answer. I do consider myself to be in a privileged situation, but apart from this relationship making you feel rather special, accepted and valued, I also feel it to be a natural relationship. I believe this natural feeling comes from the fact that we at the University Hospital have an enviable team of like-minded professionals that look to provide the best care possible for their patients, bringing together all the ingredients required to speed a patient's rehabilitation. This belief flows from the very top of the team right down to us visitors and it shows with patients being more positive, often commenting on how the consultant sat by the bed and took the time to explain things in explicit detail using terms and a language that they could understand. Every aspect of patient care is looked at and the best option implemented. When the patient sees and feels this it makes the whole hospital journey a shorter less stressful affair saving the NHS time and money and returning the patient back to an active lifestyle sooner rather than later.

I don't think I can answer to the question "At what level do I work alongside medical professionals?" as I am not in a position to pass an opinion on myself and what I do. I would like to think that in a way I and my fellow visitors are valued, that our positive outlook on a procedure that in most cases changes your life forever is something that a medical professional can use in a positive way when talking to a patient and their family. Our ability to access and provide ongoing support, advice and friendship through our National Associations makes up a small part of their package of care. For me at least I would consider myself to be just one of the ingredients of a very comprehensive, ongoing package of care that our hospital provides and irrespective of qualifications or experience I am happy to remain a small player in this big production. However, I will always be in awe of these remarkable healers.

Q9: At any point did a medical professional feel threatened by your presence?

No, not at all. If I felt that my presence was perceived as a threat in any way or at any level I would consider myself to have failed in a very big way. It is something that would make me consider stepping down from my voluntary work. Any qualifications I have from the courses, workshops and seminars I have attended over the years do not in any way qualify me to get involved in a patients care at any level to pose a threat. Something like this goes against all the fundamental principles of being a voluntary visitor.

Q10: At any point did a patient feel threatened by your presence?

I have never felt that a patient was feeling threatened by me and hope I never will. A great many things influence how a patient sees, and to a degree embraces, a visitor from where we position ourselves - not standing over them or being too close which could appear threatening - being aware of the volume and tone of voice - this can be a distraction as well as an embarrassment - monitoring body language by relaxing and adopting an open, friendly body position, and when talking to the patient remembering never to use our own standards and beliefs as a benchmark as another person may have a different set of values and priorities.

To begin with I introduce myself as a patient volunteer, ask if they feel OK with me talking to them. Then as you start to talk you find that most patients "take you where they want to go". Most of the time when they realise that you also wear a pouch they tell you about their feelings then ask if you experienced something similar. However, we all come across the situation where you feel a clash of personalities or you feel that your face doesn't fit. It could be that one of you just feels uncomfortable. If this happens I tend to choose the right moment to bring the conversation to a close, offer my card and an appropriate literature pack and arrange for another visitor to attend if required so they have something positive to take from the visit. Almost all of the people that we see are told about the patient support group by the Stoma Care Team and anyone not wishing to have a visit is noted and the voluntary groups are informed in advance.

Q11: How do you think your work benefits the patient and/or medical professional?

This question was kindly answered by a very good friend of Tidings - Julie Rust. RGN. BSc. MSc. Here is her view of the key role Volunteer Visitors provide at the University Hospital of North Staffordshire NHS Trust.

We see our visitors as playing a vital part in preparing patients for stoma surgery and supporting them in the pre and post operative period, both as in-patients and at home.

We have an extremely efficient referral system for all our patients. Every week our co-ordinator, Mr Ernie Hulme, contacts the Bowel Care Nursing Team to obtain a list of any new referrals and also a list of current in-patients requiring a visit from a volunteer. All patients are passed to Ernie, irrespective of type of stoma, and he allocates a suitable visitor who will then visit the hospital to see the relevant patients.

Ernie can also be contacted at other times to arrange visits to see people prior to admission and also to visit patients on the ward who we feel need extra support. We find our visitors can continue the follow-up care in the community once they have completed the formal follow-up by the nursing team and are very

Pictured above is the Bowel Care Nursing Team. from left to right: Michelle Spencer SCN, Julie Rust Clinical Nurse Specialist Stoma Care, Deanna Latham Colorectal Clinical Nurse Specialist and Michelle Amos SCN.

good at identifying potential problems and referring patients back to us for an appointment in the Stoma Care Clinic.

Patients need a seamless transition back into the community and we find that the support they get from our volunteer visitors is greatly appreciated by the patients and their carers, as well as providing us with the information about how we can continue to improve the service.

Our visitors annually help us to review our service in the form of a Patient Party which provides us with some extremely useful information which we use to improve patient care. This meeting is held annually to discuss with patients how we have implemented the changes they suggested and to try to identify any further developments they feel is necessary.

Without our visitors the quality of the service to patients would be greatly diminished and the support patients receive from a visit from who we see as the “True Experts” would disappear.

Overall our visitors provide;
Support – to patients, families and the Nursing Team. Practical Advice – are able to offer ‘real life’ advice but know when to refer to the specialist nurse. Friendship – they offer friendship to patients who are vulnerable and need the support from people who are not medical. Inspiration – they show the patient it is possible to return to an active, fulfilled Lifestyle.

(Special thanks go to Julie Rust. RGN. BSc. MSc. Clinical Nurse Specialist (Stoma Care) University Hospital of North Staffordshire for taking time out of her busy schedule to give Tidings readers this insight.)

Q12: Do you think other volunteers could learn and benefit from your experiences? If so, why?

Yes. There are so many different aspects of providing support that one of the many facets of the role could be used in most if not all hospitals. If you are unable to gain access to the wards look at the journey a patient makes and find a spot or entry point where you can provide literature or hands on support. Central Outpatient Departments, Treatment Suites, Radiotherapy Departments, Chemotherapy Wards, Scoping Suites where colonoscopies are carried out, Cancer Information Centres, Gastroenterology Wards, Clinics and so on, are just some of the areas you can concentrate on. For my part I am always willing to share my experiences with any volunteer wanting help or advice. I am sure, should the need arise, that one of our hospital’s specialist nursing team would respond to a request from another Bowel Care Team to explain how volunteers are incorporated into the package of care and what legal and NHS requirements need to be put in place when looking to set up a visiting team.

Q13: Do you think other hospitals and medical professionals could benefit from your experiences?

Yes. The facts speak for themselves. With the healthcare professionals having the patient volunteers to call on, new patients accept their stomas a lot quicker. It can help in part to reduce hospital recovery time and the patient’s return to an active, fulfilling lifestyle. Other areas where volunteers can benefit medical professionals are through such services as the Out of Hours Helpline which can help reduce the number of post operative calls or visits to the hospital with lifestyle issues, work and social problems and relationship matters. Compared to the healthcare professional a volunteer has fewer restrictions on their time.

Q14: What in your opinion makes a good volunteer.

Many things.
Time: You must have had the time to understand and come to term with your own stoma - twelve to eighteen months being a minimum - and where possible have an ongoing relationship with your stoma care nurse or nursing teams.

Commitment and dedication:
You need to set aside time and be prepared to support someone sometimes for as long as is needed. You must be a good listener and have the ability to empathise. You must also to be aware of your abilities and limitations and be prepared to embrace supervision and continued education.

Volunteers must also exercise, and be seen to exercise, discretion and confidentiality, truthfulness and compassion.

Our main qualification has to be our own experiences of life with a stoma; this is one aspect of this life-changing procedure that, for the healthcare professional, education cannot provide.

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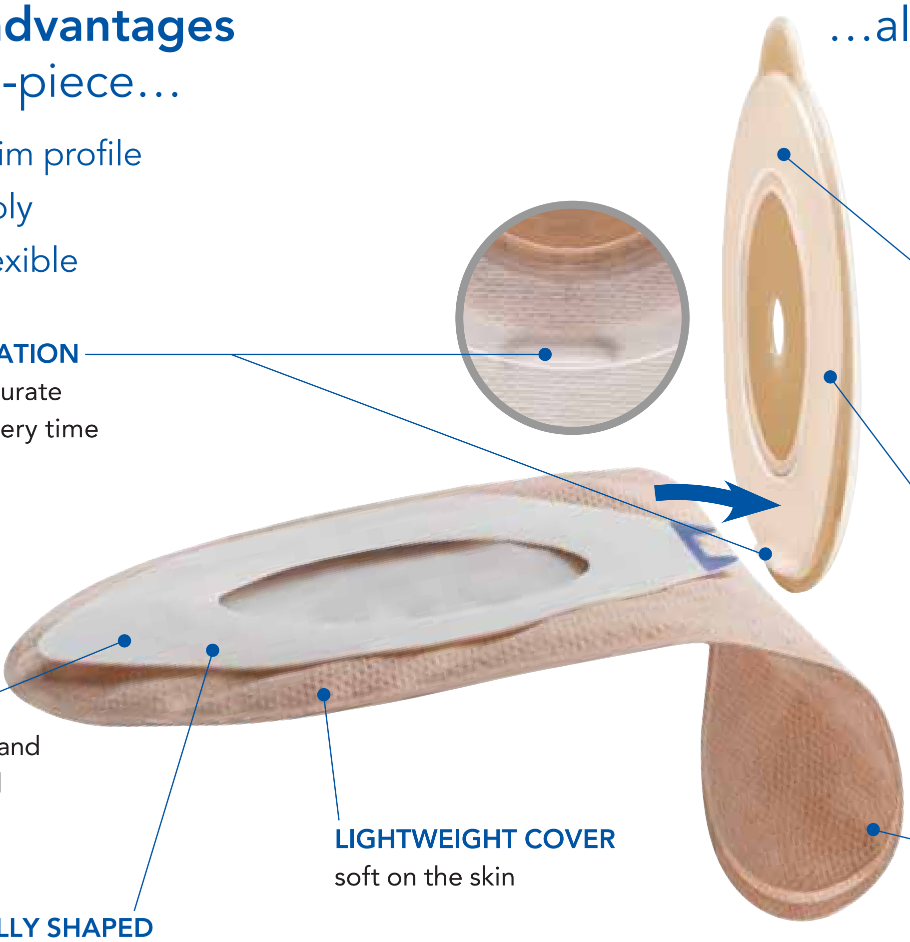

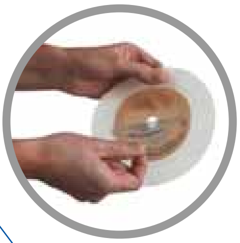

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Snapshots of the events held for
World Ostomy Day 2009

The CA and WOD 2009

Volunteers from the CA around the country joined in to support World Ostomy Day 2009 at the four events nationwide. Glasgow, Manchester, Reading and the final event held on the 3rd October, which was World Ostomy Day, at the Bullring in Birmingham.

The event in Reading was attended by Jackie Dudley, Trustee and our volunteers Colin Alum and Heather Simister. All were on hand to chat, support and clarify what being an ostomate is all about.

There were items on sale in support of the day. Pin badges, wristbands and attractive shoppers. The funds raised from the sale of these items will be divided between the patient associations CA, IA and UA.

These items are still available for sale contact the CA office for more information...

Breakaway...proud to play their part

After talking to Anne Demmick of the IA at WCET UK in Coventry I offered to help out at the event in the Bullring, Birmingham, and took along another Breakaway Trustee, Trudy and her daughter Jasmine.

I must say we went along to this event a little nervous – as we were alongside the three main patient organisations. I was not sure what to expect but I liked the sound of it, Hannah and Jasmine were so excited.

The thought of standing in a huge shopping centre on the busiest day of the week, would fill most people with dread, to us however it is what Breakaway is all about - people with children - families. To have a child born and after a few hours they have surgery and are given a stoma, is possibly the scariest time for a mother and father. If by being there I could 'reach out' to one family then my days mission was complete.

Well, I got so excited when a mum pushed a push chair towards me and started telling me all about her son's stoma (the little boy was about three). I was able to tell her she was not alone. I assured her there were many people who would help and support her and her family. Hannah calls these people her "Breakaway" family, and that is really what they are to her, a family - a family of people who understand. I exchanged contact numbers and have since spoken to the family, who will be joining *Breakaway in May 2010 in the National Forest.

We all came home on the train feeling really positive, the girls chatted excitedly about the little boy they met, and I felt that my day's mission was done. I truly felt humbled to have been able to take part in such a fantastic event! We have never kept Hannah's condition a secret and nor does Hannah! Hannah is what she is, and we love her for it, I feel quite proud to say that Hannah, Jasmine, Trudy and I were able to help out with such a fantastic event.

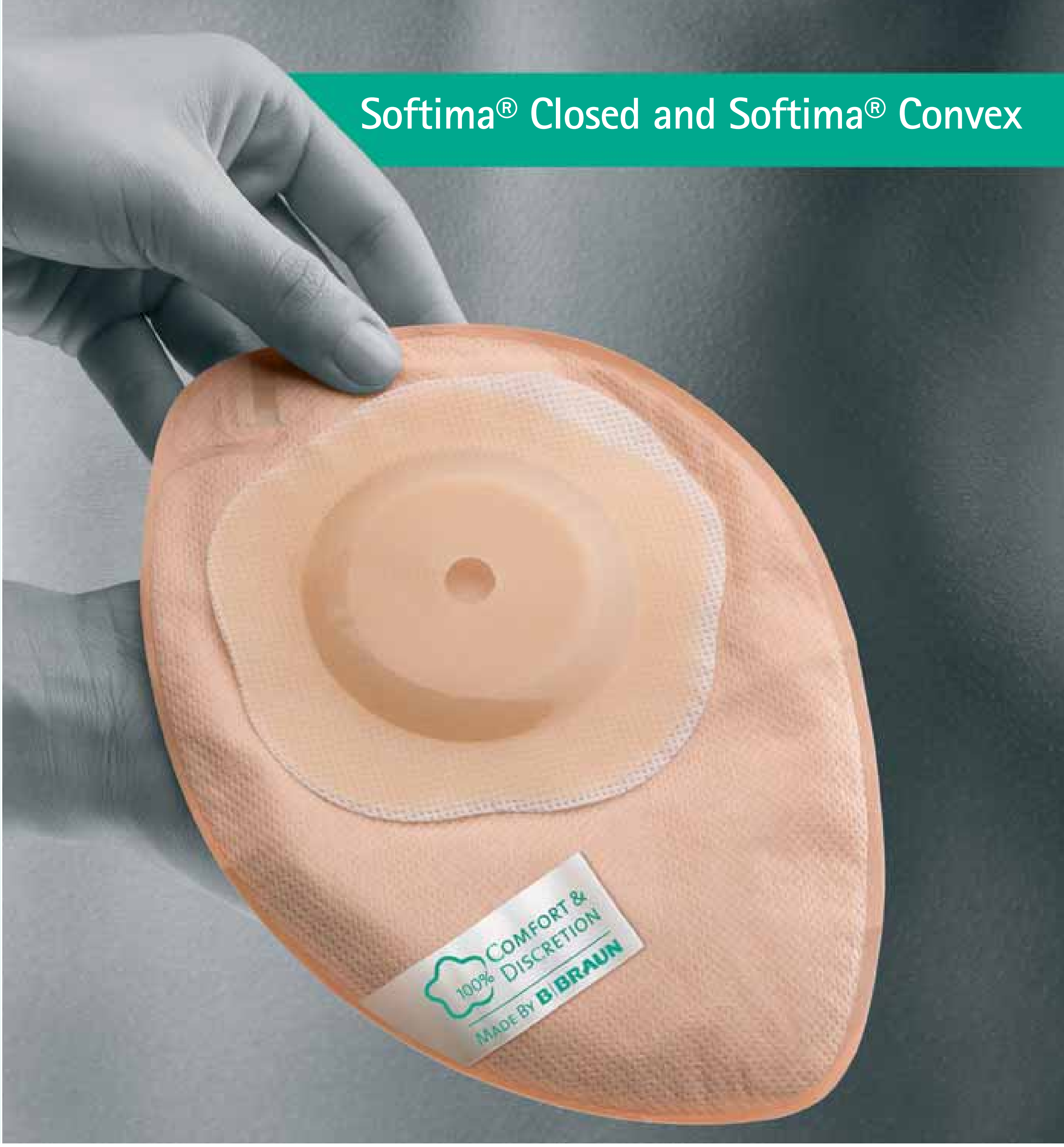
As Hannah and Jasmine would say "it's only poo!"

Julie Bastin
Co founder and trustee
Breakaway Visits
http://breakaway-visit.co.uk
Break.away@tiscali.co.uk
07939 690311

Many other events took place in the UK by companies, nurses and support groups in aid of WOD 2009...

CliniMed held a World Ostomy Day Fashion Parade to celebrate the day...

The World Ostomy Day Fashion Parade was held on 3 October at the Eden Centre, High Wycombe. House of Fraser supplied the clothes for fifteen ostomate models, with make-up by Clarins and hair by local hairdressers Sassy & Co. There were some well known personalities amongst the line up: Pam Flint who is Dennis Waterman's partner and Hannah Waterman, his daughter. CA was represented by Monty Taylor, Richard Bray and volunteer Heather Simister.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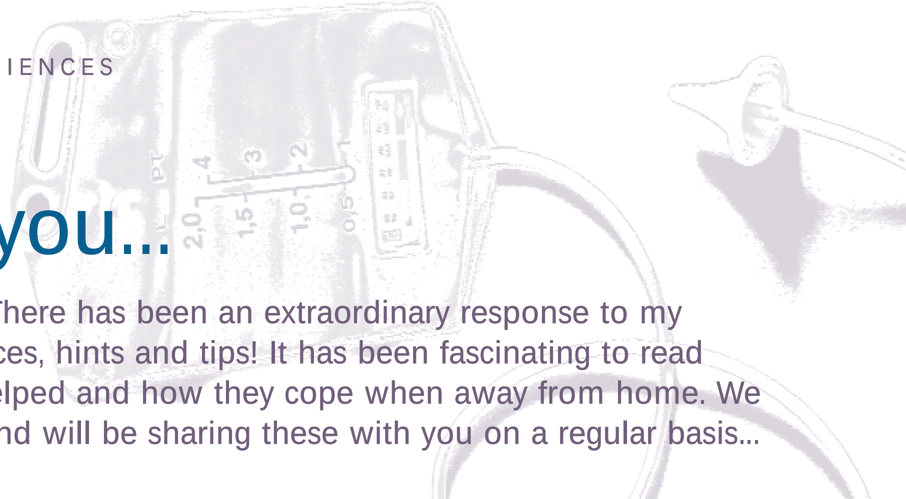


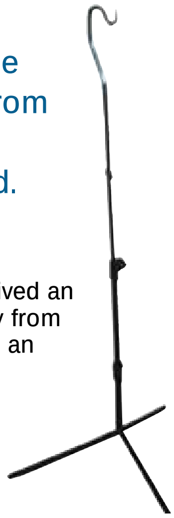
Irrigation and you...

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

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

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

I hope you find the correspondence from Dorothy May as fascinating as I did. Read on...



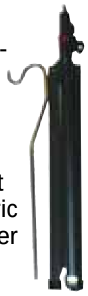
In February Tidings received an email from Dorothy May from Nottingham in response an article about Irrigation.

The correspondence follows:-

Dear Editor,
I am sending photos of a stand my husband made for me to hang my water bag on when irrigating. It is made from a good quality music stand, and the whole thing folds up small enough to go into a computer bag for transport along with the rest of my equipment. I now use an electric pump so it means I don't need it anymore. However, I was never stuck for somewhere suitable to hang my water bag, and I still have it for emergency use.

Yours,
Dorothy
Nottingham

Dear Dorothy,
Thanks for sharing this with us - what a fantastic idea! Would you mind if it was published in Tidings I'm sure it would be helpful to others who irrigate. I would love to know more about how you get on with your electric pump and why you changed over to it. Look forward to hearing more.



Editor
Tidings Magazine

Dear Editor,
Sorry for the delay in replying to you, the reason is we are on holiday up in Scotland and only picked up your message today. We would be happy for you to publish this information as I found it a great asset if I was away from home. I never had to worry about what facilities there would be. I also found the computer case ideal for carrying all my equipment as well as the stand, and it was totally neutral in appearance. We would be happy to give advice on how to adapt the music stand to anyone interested.

As far as the irrimatic pump is concerned, I have been using it for about 5 years now, and find it brilliant. I have very little peristaltic action in my bowel and find that under normal circumstances I only have to irrigate every 3/4 days. Obviously when I go away things can alter a bit because of the change of water, but I guess everyone finds that. I have cut down tremendously on the equipment I need to order, and although I had to pay for the pump, I think it is well worth it. The initial cost was around £290.00 being exempt from VAT, but I have just ordered a new one and the price has come down to £264.00

We have a motor home and although the toilet is pretty small I can manage without too much difficulty. We went to New Zealand for 4 weeks touring in a hired motor home in November 2007, and I had no major problems that I couldn't overcome. I hope this helps.

Regards,
Dorothy
Nottingham

Thank you Dorothy...wouldn't it be great if one of the stoma product companies designed and manufactured something similar for all of us. How easy would that be!

Also, from from Dorothy...in response to Sonia Woolven's article - Pathways to a colostomy, surgery in the USA and irrigation (Tidings issue 13).

I have been irrigating using Braun's Irrimatic pump for over 5 years now, and I found I used considerably less bags day to day. Has Sonia ever considered using a drainable bag after irrigating until all the effluent has finished? This is what I do, and I find it works well and also saves skin problems from frequently changing a closed bag. I also use B.Braun's one piece Iryflex sleeves which I get on prescription, as the two piece variety recommended with the pump have to be bought privately, and are very expensive.

Thank you Dorothy - Great feedback about the B.Braun Irrimatic pump! If you haven't tried one, then why not ask your stoma care nurse if she can arrange a free trial with B.Braun. Please write in to let us know how you get on.

Calling all stoma care nurses - it would be great to hear from you too. There were so many of you at the WCET UK Conference who were dedicated teachers of irrigating and others who were honest enough to admit they didn't know enough about it and would like to know more.

I have also been in further talks with Coloplast about an educational programme to teach stoma care nurses how to help patients to irrigate. It is a very exciting project, I hope to tell you more about it in the New Year!

Professor Joy Notter, who I met at WCET UK told me that all patients in Holland are told prior to surgery, that irrigation is a possible way of bowel management, as long as their surgery allows it. Wouldn't it be great if all our Colorectal surgeons and stoma care nurses followed their lead!

Here are a few hints and tips from irrigators...why not write in and tell us what works for you!

"I usually irrigate every other day, but about once a month I do the procedure every day for 2-3 days, as this gets rid of any build-up".

"I find that eating at least 5 pieces of fruit each day does help in keeping the flow going, sometimes a little more can be helpful".

"The first thing is to relax, deep breathing can be one way, some people like a cup of coffee or tea".

"After you have flushed out the sleeve, gently dab your stoma and the surrounding area with a wipe. Sometimes just dabbing your stoma encourages that last little output".

"Not exactly a hint or tip but, in the issue 13 of 'Tidings' it was stated that you should have a stoma on your left side to irrigate; my original stoma was on my left, but due to problems following surgery for a parastomal hernia I had to have it moved to my right side. I am still able to irrigate, although not always as successfully as when my stoma was on my left".

Tidings thought it would be interesting to find out a little more about irrigation and how it developed, it wasn't easy information to find but here goes…

Early times…In the 18th century the administration of an enema through the colostomy, or 'irrigation,' was suggested by Pillore and Fine as a means of regulating the passage of the stool and flatus with the intention of establishing predictable bowel habits. However this technique did not gain popularity until the 1920s. In 1924, Dudley Smith, a California surgeon, and John Greer, who worked for a surgical supply company, developed the Colostogator. This device, which consisted of a metal cup held around the colostomy by means of a belt, was the first commercially available irrigation system. Attached to the cup was a long rubber sleeve that ran into a bucket placed at the patient's feet. A rubber catheter placed through a hole in the sleeve irrigated the colostomy. With this device, patients were able to irrigate once every 24 hours; between irrigations, they wore a "simple belt of plastic webbing" with several pieces of absorbent paper.

In 1927 a surgeon J. P. Lockhart-Mummery at St. Marks Hospital, London was the first to describe irrigation in Britain and was a strong advocate of this technique. Irrigation enjoyed sporadic popularity over the next few decades. Then in the 1940s, an American music teacher, Sophia M. Secor, became an important spokesperson for the irrigation method. Her poignant articles describe the difficulties she encountered while learning to care for her own colostomy, and detail her work as a colostomy counsellor at Beth David Hospital in New York.

During the1980's in America, Enterostomal Therapists became integral players in the management of ostomy programmes in the areas of education, teaching colostomy irrigation as an alternative rather than the norm, routinely prescribing the appliance. Modern irrigation equipment uses a cone rather than the insertion of a catheter. This method has reduced the incidence of complications when carrying out irrigation and made the procedure easier.

In the UK today, irrigation is still largely under-utilised. Clinicians may not always put forward patients for irrigation due to lack of knowledge and/or confidence in teaching.

However, colostomates who can irrigate often report a better quality of life. It is after all about choice and by making the patient aware of what is available they can make informed decisions about what is right for them.

Editors Comment

If you would like to share your Irrigation experiences or have any hints or tips please contact us
e-mail:
editor@colostomyassociation.org.uk
or write to:
Colostomy Association
2 London Court East Street
Reading RG1 4QL

Online clinicians – addressing Individuals' questions via a community website

Before and after stoma surgery, people face a number of emotional and physical challenges. They often have questions about stoma care, ostomy products, ostomy-related issues, and lifestyle matters — ranging from the simple to the complex. How should individuals generally prepare for surgery? What is the recovery process typically like? How do people find the right products and learn how to use them properly? How do ostomists solve leakage problems? Getting answers to these questions is not always easy.

With average hospital stays in the UK decreasing, time for education may be limited. However, even when the opportunity for more comprehensive education is possible, people may not retain the information communicated to them in the hospital due to the stress and exhaustion associated with surgery. Additionally, some people may be reluctant to seek answers from a clinician if they live in a remote location, are busy, or are hesitant to bother him or her. Ideally, ostomists would connect with a clinician in person when they have an ostomy-related lifestyle or product question. However, this is not always possible. Fortunately, there is another option: connecting with a clinician online.

Internet access in UK households is quite prevalent, and many people are seeking out health-related information online. Submitting ostomy-related lifestyle and product questions to a clinician online can be very convenient — this path provides access from the convenience and comfort of home or work, the ability to ask a question 24 hours a day, seven days a week, and the option to remain anonymous, if desired, providing a level of privacy that is important to some.

- **The average hospital stay in the UK decreased from 6.3 days in 2006/2007 to 5.7 days in 2007/2008, continuing a long-term trend.[1]**
- **Due to these increasingly shorter stays, education may often be limited to basic "survival skills."[2]**
- **In 2008, 65% of Great Britain households had Internet access (versus 46% in 2002)[3]**
- **34% of recent UK Internet users ages 16+ sought out health-related information online (versus 27% in 2007).[4]**

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One place where people can access clinicians online is **C3Life.com**℠ — a community-based website for people with ostomies, their carers, and loved ones. C3Life.com offers an "Ask the Clinician Panel" feature that allows individuals to submit ostomy-related lifestyle and product questions to a group of clinicans.

Receive a C3Life.com shirt holder at no charge when you sign up or update your profile on www.C3Life.com/Tidings — one per person. While supplies last.

Ostomy Online Community

Where can I find information and support?

Where can I connect with people who understand?

Where can I share my experiences?

C3Life.com is your new ostomy Community Connection Center – a website for people with ostomies and their loved ones.

It's a place where you can get inspiration and support from people who understand your concerns, and where you can receive the rewards of sharing your experiences with others. You're invited to visit C3Life.com today and join the community.

www.**C3Life**.com/Tidings

Information **Support** **Connections**

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To pose a question, individuals must supply the Panel with background information, including their location, type of stoma, age, gender, and length of time since surgery. They can choose to supply their real name, or a screen name (a pseudonym used when communicating with others online) if they prefer the privacy of that approach. Panel clinicians typically respond within approximately 72 hours or less, and recommend face-to-face consultations with a Stoma Care Nurse and/or physician when appropriate. Additionally, all questions and responses are posted on the site so that individuals can learn from the experiences of others.

A sampling of user-submitted questions to the C3Life.com website can be found below:

"I'm a new ostomist and am just wondering if it's better to shower with the ileostomy bag on or off?" – Submitted by reduntildead, Posted 06/07/2009

"My Mother has had a colostomy for a year and a half. It seems to work fine for a while and then all of a sudden it starts leaking no matter what they try. She has tried one and two piece systems (paste, tape, etc) and sometimes nothing seems to work. Any suggestions?" – Submitted by jreliason, Posted 06/07/2009

"I have had a temporary ileostomy for about 3 months. My husband and I just resumed having intercourse about a week ago. The other night my skin barrier came loose and I had a leak. How can this be prevented next time?" – Submitted by katandbob, Posted 23/04/2009

Amanda Smith
BSc, ENB 216, RGN, RSCN

Amanda Smith (BSc, ENB 216, RGN, RSCN) has been a member of the C3Life.com "Ask the Clinician Panel" since the launch of the website in 2008. She has been a Stoma Care Specialist Nurse for over 14 years and currently works at Salford Royal Hospitals Foundation Trust in the North West of the UK in Salford. Amanda had this to say about the benefits of the C3Life.com "Ask the Clinician Panel":

"At the hospital, you answer the questions patients are asking, but they don't always absorb it all," Smith says. "It's an intense situation and they're receiving a lot of information."

Smith knows from experience that many ostomists continue to have lifestyle and product-related questions – even months and years after surgery. "They may not know how to get in touch with a local nurse, or may be reluctant to contact him or her on a holiday or over a weekend," she says. "It's a good way to provide information to them, so they can keep living their normal lives. That's why I became involved with the Panel."

The following comments highlight how appreciative ostomists, carers, and nurses are of the responses provided by the clinicians on the C3Life.com "Ask the Clinician Panel":

"Thanks so very much for your suggestions. Nice to know you all are here to help!" – Submitted by Nateysmama, Posted 16/1/2009

"I think it took me longer to type my previous question, than the time it took you to answer it! Thank you very much for your time, help, and thoughts." – Submitted by francisco, Posted 24/11/2008

"There are not too many resource persons that I can seek help from, so I am always happy that you all are a click away." – Submitted by simple, Posted 16/7/2008

"Thank you for the access to others' questions and your suggestions. It helped us to realise that many of the problems we have been experiencing are typical of an ileostomy, and can be handled." – Submitted by homehealthnurse, Posted 24/2/2009

"This is an awesome website. It is so nice to be able to ask questions and get answers." – Submitted by missnancy48, Posted 17/6/2008

"I think your site is excellent – I didn't realise so many people had the same problems as myself." – Submitted by CAROLTOM, Posted 19/5/2009

"Some people don't want to be dependent on their local Stoma Care Nurse — they pride themselves on being independent, or they don't want to trouble you because you're busy. The C3Life.com 'Ask the Clinician Panel' is a great resource for people like them." — Michele Dade (RGN, Dip.Healthcare Ethics, ENB 216) Royal Bolton Hospital, Bolton, UK

Finding information and support can be a challenge for ostomists. Today, there are more ways than ever to find both. Websites like C3Life.com offer an opportunity to connect with a clinician online — helping get answers to ostomy-related lifestyle and product questions so that individuals can get back to the business of living their lives.

1. Hospital Episode Statistics HES (admitted patient care) England 2007/2008. NHS Online Information Centre. 2/25/2009.
2. Turnbull, GB. Is There a Gap in Ostomy Rehabilitation? OWM. 2006.
3. Internet Access 2008. Office for National Statistics. 8/26/2008.
4. Internet Access 2008. Office for National Statistics. 8/26/2008; Social Trends. Office for National Statistics. 2008 Edition.

CA attends the World Council of Enterostomal Therapists UK (WCET UK) Conference 2009 held at the Ricoh Arena

Every year WCET UK organises a phenomenal conference attracting an eager audience of over 350 nursing professionals specialising in stoma therapy.

The theme of this year's conference was 'a problem shared'. Keynote speakers covered areas such as:
- Psychosocial issues (including sexuality and body image)
- Dysfunctional bowel
- Intestinal failure/High output stomas
- Innovations in surgery with a particular interest in small bowel transplantation

A team four strong made up of Sue Hatton, Jane Wood, Richard Bray and Chairman Monty Taylor represented the CA at the WCET UK Conference 2009. The CA was very kindly sponsored by CliniMed. CA exhibited along side the other patient associations, and were able to sit in, and listen to an amazing programme of educational sessions led by prestigious speakers from the world of stoma care.

Many commercial companies attended and there was an area especially set-aside for exhibitors which provided everyone attending, including the CA, with an opportunity to update themselves on new stoma care products and accessories. There were also two awards to be won, the Opus education award and the Salts nurse recognition prize.

The first presentation we attended was a Satellite Symposium organised by CliniMed and given by Robin Kennedy, FRCS, MS, MBBS, a consultant colorectal surgeon at St Mark's Hospital and The North West London Hospitals NHS Trust and Jennie Burch, BSc, RN, an enhanced recovery facilitator from St Mark's Hospital London the subject *Enhanced Recovery After Surgery* (ERAS). Enhanced recovery is a multimodal pathway of care that involves all the multidisciplinary team. There are 17 elements (plus audit) that are important to understand.

Elements of the enhanced recovery pathway include;

- Pre-admission information
- No oral bowel preparation before colonic surgery
- No prolonged fasting
- No long-acting pre-medication
- No nasogastric tubes immediately after surgery
- Thoracic epidural analgesia
- Anaesthetic techniques that allow early recovery and minimise nausea
- Changes in perioperative fluid management
- No drains
- Active warming during surgery
- Early mobilisation after surgery
- Improved post-operative analgesia
- Prevention of nausea and vomiting
- Stimulation of gut motility
- Early removal of urinary catheters
- Early post-operative feeding
- Providing a helpline after discharge during the first two weeks
- Audit of compliance

Enhanced recovery is not a new concept – it has been carried out for over a decade in Europe. In the UK, it is rapidly being implemented, particularly by laparoscopic surgeons, such as those at St Mark's Hospital in Harrow, Middlesex. Colorectal surgeons who choose to perform open surgery can also use elements of the package. Although some centres may be able to discharge patients home safely after only two days following laparoscopic bowel surgery, a target of 3–5 days after surgery is more realistic. Following open surgery, a few extra nights in hospital are usually necessary.

There are a number of colorectal operations that can be performed.

Types of colorectal surgery included;
- Abdominoperineal excision of the rectum (APER/APR/AP) with colostomy
- Anterior resection +/- loop stoma
- Colonic resection
- Hartmann's procedure with colostomy
- Subtotal colectomy (STC)
- Total colectomy with ileostomy or ileo-rectal anastomosis (IRA)
- Panproctocolectomy and ileostomy
- Ileal pouch-anal anastomosis (IPAA)

Sue Hatton gives us her observations on this Symposium…as a Colostomate with no medical background I found that the team involved in the pre surgery assessment had not taken into account the emotional trauma of having a stoma. There was no offer of counselling or advice on body image or sexuality issues that post operatively some patients may need to discuss with a therapist. I would like to draw your attention to the work of Dr Isabele White, European institute of Health and Medical

About… World Council of Enterostomal Therapists UK (WCET UK)

WCET UK is a charitable trust, established in 1995, to promote the art and science of stoma care nursing (and related conditions) and to improve facilities and opportunities for nurses and others engaged in such care to further their education and skills in the profession of stoma therapy nursing, thereby ensuring specialised nursing care for all people with a need for such care.

WCET UK is a member organisation of the World Council of Enterostomal Therapists (WCET) which internationally encompasses continence and wound care in addition to stoma care.

WCET UK is the only professional organisation solely for nurses with an interest in stoma care and related subjects.

Sciences (EIHMS) University of Surrey and Macmillan Clinical Nursing Research Fellow who presented research at WCET UK on psychosexual concerns in clinic. Her research suggests that generally surgeons and nurses fail to take into account the importance of sexual well being admitting that they felt inhibited in talking about sexual concerns with their patients prior to surgery.

Sue comments on the benefits and the negatives of ERAS;

Benefits;
- No bowel prep
- Fluid and Cho loading so no fasting ensuring that the patient is well prior to surgery and not weak and lacking fluids.
- No pre meds
- No nasal gastric tubes
- Patients are given a short acting anaesthetic agent.
- Prevents nausea
- There is only a short incision so there are no drains, resulting in reduced herniation.
- Patients fed on day after surgery.

Negatives;
- Problems arise if surgery is conducted at end of week. Those operated on at this point may not be assisted with the essential training days required to accomplish the removing and reapplying of a bag/pouch before the patient is independent of the nurses' assistance. Patients who have surgery at the beginning of the week will be ensured continuous stoma care management advice.
- Lack of home visits, no community nurse visit.
- Patients told to come into next hospital clinic.

Sue's queries - Should the patient be discharged if the stoma is non-active? Is the patient well enough if gas is the only indication that the stoma is operating successfully?

There were no records of readmission to hospital if there was a blockage of the bowel or trauma to the bowel, which can happen after the third day.

The presentation was however an amazing introduction to fast track surgery, which is becoming the preferred method of bowel surgery and will no doubt be more widely used as surgeons become more, experienced.

The CA would be very interested to hear from patients who have had laparoscopic surgery and to learn what their experiences were.

Points of interest we would like comment on are:-
- What information was given prior to surgery?
- Did you have confidence in being able to manage bag/pouch change?
- Was there a stoma nurse available to discuss problems arising post surgery?
- Was there any encouragement to speak with patient associations or have further counselling?
- Any instance of blockage or hernia?
- How long before you felt that you were able to reassume sexual function. Would you have liked more support, advice?

Professor Joy Notter PhD, RN, RHV, CPT, HVT, PGCEA

Also presenting at WCET UK was Joy Notter - Professor, Community Health Care Studies, University of Central England; Lecturer, Health and Welfare, Academie Gezondheidszorg, The Netherlands. Her presentation informed conference of a survey that has been conducted with almost 400 participants focusing on people with colostomies. The aim of the study was to pilot a questionnaire for a much larger study. Prof Joy has asked the CA for our help with this. The questionnaire will provide an insight into the quality of life of those who participate and will be sent out in the Spring edition of Tidings. It covers a wide range of issues that face Colostomates as they cope with the outcomes of major surgery and the disease that led to the surgery.

Prof Joy is a very warm, genuine and caring person and is very happy to be closely associated with the CA. We all felt that her influence with this research project would help us enormously in the future.

We were unable to listen to all of the presentations, but they were wide ranging and stimulating. Questions arose on accessories, convex pouches, and stunning lingerie for ostomates from Nicola Williams, an ileostomate who wanted gorgeous underwear! There were some terrible tales of heartbreaking challenges that the stoma nurses had to face when working with patients, including the use of patient stories in Service Development and the sharing of experiences in dealing with granulomas.

It was great to meet up with stoma nurses who are becoming familiar faces, especially our 'Dear Nurse' Julie Rust and Michelle Amos SCN from Stoke on Trent. The atmosphere during the Conference was electric and the Ricoh Centre was buzzing. Our thanks to all who visited our stand, picked up our 'Going Home Pack', and survived an interrogation as to whether they were up to speed with irrigation!

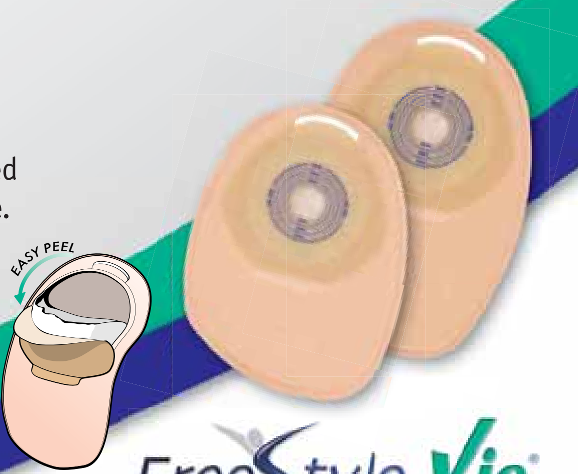
Even those nurses who chastised us for including in Tidings, the tip on pricking your stoma bag with a pin if it is ballooning and you cannot change it. We know this is not the right way of getting rid of wind in the bag but the relief of not having a drum on your tummy is immense! Also the nurse who asked if we had a leaflet on Hernias, and we said, 'No' and Jane asked if she would write one for us! Great!

The CA would like to congratulate the WCET UK committee for organising an incredible couple of days - we didn't stop, we discovered so much and met so many great people – we will certainly be back!

Editors Comment

If you would like to learn more about the event and read the conference programme visit www.wcetuk.org.uk

or would like to contact us
e-mail:
editor@colostomyassociation.org.uk
or write to:
Colostomy Association
2 London Court East Street
Reading RG1 4QL


EASY PEEL

Caring with Confidence...

Graham Brindley, Project Director at Caring with Confidence, talks to Tidings about a new, free initiative for carers in England.

One in eight adults is a carer. They can be anyone: parents, children, sisters, brothers, friends. You might become a carer overnight: every day, it is estimated that another 6,000 people take on a caring responsibility. It can be a 24/7 job and is often a thankless one, physically and emotionally draining with an overriding feeling of isolation.

Caring with Confidence is a new programme which aims to make a positive difference to carers and the people they care for, by improving their health and well-being. We do this by providing free support sessions, designed by carers for carers, where they can learn skills, get advice and information, talk and share experiences.

Caring with Confidence is part of the Government's renewed National Carers Strategy and the 'New Deal for Carers', which aims to improve support for carers aged 18 and over in England.

Throughout our development, carers have been at the heart of the programme. Alongside professionals from carers' organisations and charities, carers have told us what they wanted from the programme, trialled the sessions and provided invaluable feedback to us to make sure we got things right.

caring with confidence

How the programme works

The programme is designed to fit around people's lives and caring responsibilities. Carers can pick and choose how many sessions they attend, and how they get involved - from local face to face groups to distance learning through self-study workbooks and online sessions or indeed they may want to use a combination of all three options. Importantly the programme is completely free to carers with all their costs of participation and travel and respite care costs being paid for. The group sessions are delivered by skilled and knowledgeable facilitators and are run through a network of Caring with Confidence Providers throughout England which include carers' centres, local authorities and charities.

Our programme is made up of seven sessions covering a range of topics that carers told us were important to them. The content is the same regardless of the way carers choose to access them.

Our seven sessions are:

Finding Your Way
This introductory session helps carers look at what matters to them and explore the themes of the other sessions available to them.

Caring and Coping
Gives carers time and space to explore the emotions involved in looking after someone and the strategies to use to cope with stress more effectively.

Caring and Me
How to be fit for life and caring. Carers discuss and plan around their own health and well being.

Caring Day-to-Day
Looks at the essentials of looking after someone day-to-day, from medication to emergencies at home.

Caring and Resources

How carers can maximise their income and access other resources which save them money.

Caring and Life

Invites carers to take time out and think about how to juggle competing demands and how their caring role fits with other aspects of their life.

Caring and Communicating

Uses real-life caring situations to help carers get the best from communicating with professionals and service providers.

A bespoke programme of sessions has also been developed to specifically meet the needs of carers of people nearing the end of life and following bereavement. We are also developing further sessions aimed at carers of disabled children, carers of adults with complex needs, carers of people living with mental ill health and carers of people with dementia. We are also working to ensure that people who look after someone but perhaps don't see themselves as a carer, or who aren't already accessing any support in their caring role are made aware of the programme and the benefits it can bring them.

Making the programme accessible

Carers can often be faced with financial difficulties, unpredictable schedules and constraints on their time. Finding three hours in a day to attend a local group session can be a challenge. We try to make it as easy as possible for carers to get involved with Caring with Confidence – paying for alternative care and travel costs, running sessions at different times of the day and at weekends. The sessions are repeated so that if a carer has to miss a session they can pick it up again later when circumstances allow.

Even so, some carers may still find it impossible to attend group sessions, or may not have a group in their local area. To ensure these carers still have access to support and advice from Caring with Confidence, we offer the programme in two other easy-to-use formats: Self-study workbooks – working in collaboration with the National Extension College, who have expertise in home-study courses, we have adapted the programme into engaging, easy-to-follow workbooks. Online sessions – carers who have access to the internet at home, at a friend or neighbour's house or at their local library or internet cafe can take part in sessions online. Carers are offered support from a mentor as they work through the sessions. Both the workbooks and online sessions also include information on further sources of support which may benefit carers.

Editors Comment

If you are a carer aged 18 or over and live in England, or know someone who is and would like to find out more about the programme and how you can get involved, please visit www.caringwithconfidence.net or call 0800 849 2349

Around the world and back again...
Three colostomates go for it!

Thank you to all our readers who wrote to tell us about their travels. In this issue of Tidings we have included three of your stories about going on holiday for the first time after stoma surgery and then venturing further and further afield...

Have bag will travel...

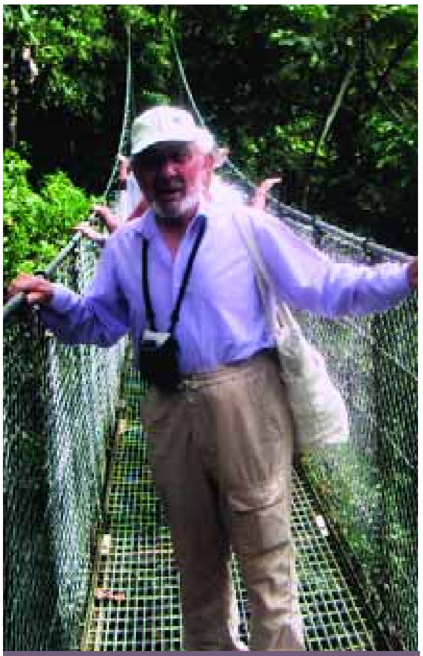
About two years ago I woke up one morning suffering from tremendous stomach pains. I was so bad that my wife wanted to call an ambulance but I said no. Instead we went to the surgery. The doctor took one look at me and said I was to go to hospital as an emergency.

In hospital I was examined by a consultant who said I had diverticulitis. I was to have an x-ray straight away and a dietitian would visit me the next day. When I arrived back from x-rays, I had just sat in the chair on the ward when I collapsed. All I can remember was lots of hands putting things all over me. Then I passed out completely.

Ten hours later I came round in the recovery room only to be told that I'd had a major operation and I now had a colostomy. The consultant came to see me next day and said that I could have the operation reversed in three months time.

When I went back to see the consultant he said yes I could have a reversal but advised against it because they had to bring me back twice during the operation and he did not want to chance a third time. But it was up to me to decide what to do.

I went home and made my mind up to keep the bag even though the operation was for a hole in the colon and could be reversed. The first thing I had to do was to accept the situation, which I did. The next thing was not to let the bag run my life, so I decided only to think about it when it needed to be emptied or changed. I did this by getting on with things as though the bag did not exist. I did the gardening, went back to dancing twice a week and rejoined the ramblers on four and five mile walks.


Crossing one of the suspension bridges deep inside the rain forest

The next step was to travel. The first time was a twelve hour coach journey to Scotland stopping every two hours when I made a dash to the disabled toilet only to find everything was all right. While there we went out on tours and then there was the long journey home, all without incident.

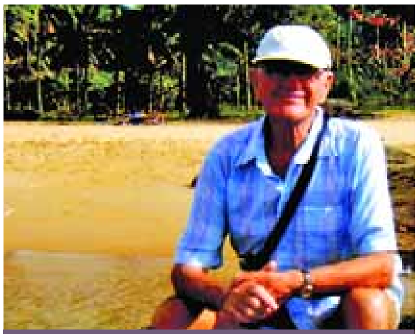
Six months later we decided to go on an eight day coach trip to Italy. There was an overnight stop in France on the way out and coming back. While in Italy I did encounter a minor problem on one day when we were going on a tour. Just as we were going to get on the coach, the bag decided to fill. My wife got a message to the driver and I changed the bag in record time. For the rest of the holiday I had no more incidents.

Seeing as how easy it was to travel we decided a three week cruise was on the cards. Again I felt that the bag really did not present much of a problem, if any. Then I decided I really wanted to push myself to the limit, so I could say I was back to normal. We decided to walk the rain forests in Costa Rica, so once again we found ourselves on a long haul flight. On the way I needed to change the bag. In the toilet it was quite a laugh trying to put the bag on while the plane went through turbulence. Apart from that there was no difference to doing it at home.

For the next two weeks we toured the country staying in different hotels. We walked in the rain forests and even above the forest - again no problems. On the third week we just chilled out before a twenty-seven hour journey home to Norfolk. This holiday was so good we decided on another long haul flight to St Lucia just to make sure I am back to normal. So you see "have bag will travel" is always a possibility.

Mr R.S. Lane

Getting away for the winter... after a colostomy


Danny enjoying North Pattaya, Thailand - blue skies and sunshine

The weekend of my 65th birthday I was looking forward to a family get-together to celebrate, before my programmed admittance to hospital for a colostomy operation on the Monday. However, Mother Nature decided otherwise and on the Friday I was admitted to the emergency ward by ambulance. On my birthday I spent eight hours on the operating table with a very experienced, hard working medical team who gave me my best birthday present ever. I am still here to talk about it.

I left hospital five weeks later and began six months of chemotherapy. Three weeks after this we flew to Thailand for a four week holiday in the sun having previously discussed this with my consultant and stoma nurse who said, ‘Go for it.’

Having an eleven hour flight and allowing for three hours booking in time, I was wondering how I was going to cope. What was my bag going to do? As a precaution I did change it en-route but all was well on the flight.

At first I sat at a table in the corner of the restaurant of the luxury hotel where we stayed…just in case I caused any embarrassment. After a few days I realised it was not a problem and happily sat eating and talking with other guests.

Each winter since then we jet off to the blue skies and sunshine for three months. This year we made a trip to an orphanage in North Pattaya where we met and spent three enlightening days with a group from our home parish in Maidenhead. The Father Ray Foundation/Redemptorist Society Orphanage is an amazing charity. It has a seven acre site and caters for 750 individuals. There is an orphanage, a nursery, a school for the blind, a school for the deaf, a drop in centre for very poor pre-school children and a training centre to help disabled young adults find employment. It was a very moving experience for us.

So if you have a stoma and are thinking of a holiday, take your doctor’s advice and “Go for it”.

Danny Maxwell

Travelling with a stoma… be prepared

Wendy and her husband John pictured with the pilot of a float plane - Canada

My first post-stomal trip began just nine days after I came home from hospital - when my stoma was just sixteen days old. John, my husband, and I had already booked a self-catering holiday in Devon. Both my stoma nurse and the hospital doctor could see no problem, so off we went, travelling from Southampton to South Devon. Lesson number one occurred on the way down (or rather later that day) as we had stopped for a light lunch. The soup turned out to be very spicy – not a good idea as it happened – but I put that down to experience. Fortunately I had plenty of supplies with me.

When we had arrived and unpacked I looked round the bathroom to work out where to lay my kit so I could set up my routine. We really enjoyed our week away and felt all the better for it, going out for days and finding that life with a stoma still goes on. I naturally took a small cosmetic-style bag, which fitted snugly in my handbag, out with me each day…so I was never unprepared.

Our second holiday that year was much more adventurous, as it involved a short flight from Southampton to Jersey, then a week in a hotel – a double whammy. I had no problems going through security. I simply showed my little card stating I was carrying necessary medical supplies and went straight through. The flight was completely uneventful and I didn’t even think about my stoma. Our room in the hotel was en-suite, something I would recommend every time, as you can leave your bag of supplies in the bathroom ready for use.

Next, we took a short break coach tour to the German Christmas markets. Changing my bag on the coach was an experience, but presented no problems in spite of the cramped facilities.

In September of this year, we undertook a long-haul flight to Vancouver in Canada. As we were going to be away for three weeks I naturally wanted to take lots of supplies with me. I put plenty in each case (in case one got lost) and took extra in my hand luggage – again I was prepared. Changing my bag on the plane was no problem.

Needless to say, we had a really wonderful trip touring the Rockies - two days on a train, and ten days on a coach. We had en-suite rooms and food I could eat – if I couldn’t understand the menu, I just asked what a certain dish might contain.

So, I have a stoma - believe me, it’s no big deal. I wear a medic-alert bracelet, always carry a RADAR key and a “need to use the loo in a hurry” card, which has never failed me. Travel, therefore, boils down to one thing: Be prepared. Life is for Living. There’s a whole world out there, so, if you are able, go out and enjoy it.

Wendy Hayward

Why write in and tell us about your travel experiences or give us your hints and tips…

A Colostomate Comments...

New to 'Tidings' - a regular column which raises and researches the issues associated with living with a colostomy. If you would like 'Tidings' to discuss a particular topic or issue that affects you day to day why not write in or email: associate-editor@colostomyassociation.co.uk

Cruising is probably one of the most convenient ways for a colostomate to travel abroad – wherever you go your bathroom goes with you – but there is one issue about which there is some debate: Can toilet-disposable colostomy bags be flushed down the loo on a cruise ship… or, for that matter, an aeroplane?

At present there are two flushable pouches on the market and I think that, like myself, most colostomates are looking forward to the day when all manufacturers produce stoma appliances that can be disposed of in this way.

Dansac have recently introduced a flushable pouch as part of their NovaLife 2, two piece system. In their leaflet they state:

"The inner pouch with contents can be flushed away in any toilet. It is environmentally friendly and will biodegrade naturally. " When I queried what was meant by "any toilet" I was told it meant any system that could cope with toilet paper. The inner liner breaks down due to the joint action of water and the bacteria in the pouch contents.

The Welland one-piece flushable pouch has been around for many years. In their literature CliniMed are more specific:

"The FreeStyle Vie Flushable inner liner is designed for simple, reliable disposal in any toilet – at home or abroad, at sea or in the air. Safe to flush down all domestic toilets (including septic tanks), portaloos and vacuum extraction systems, the liner begins to dissolve the instant its outside surface comes into contact with water. All you are left with is the clean outer pouch."

However, on a recent cruise, there in the en-suite, was this notice:

If anything other than toilet paper is deposited into the toilet, it will likely clog. Repair costs may be passed on to you if objects have been intentionally disposed of in your toilet.

There were also a couple of incidents where the ship's plumbing became blocked. For those people in cabins close to the affected area the odour was quite unpleasant. The problem was rapidly and efficiently resolved, I have to say, but the ship's grapevine made sure that passengers, even those on decks far removed from the incident, knew all about it. Some people could even pinpoint the cabin and the culprit! I certainly wouldn't have liked to be in their shoes.

So what is the answer? Can we flush our toilet-disposable bags down the ship's loo or not? The Colostomy Association contacted Carnival UK, the company which includes P&O, Cunard, Princess, Holland America, Ocean Village, AIDA and Costa, and received the following reply from one of their Technical Superintendants:

"Our vessels all have an EVAC vacuum toilet system. The system is designed to operate with a minimum amount of water in the disposal pipe-work, which is held under vacuum. All matter entering the system from the toilet bowls must breakdown through the force of the vacuum. Water in the toilet bowl only acts as an initial lubricant in the disposal pipe-work and does not play a significant part in the breaking down of any disposed matter from the toilet bowl."

So here is the challenge: can our manufacturers convince the cruise liner's technical experts that their product will pass the toilet test or, if not, can they come up with a new design that will?

What we really need now is to hear from you – colostomates who have been cruising. Please write and let us know about your experiences and we will include a selection of your letters in the magazine and pass your comments on to the manufacturers.

In the meantime disposing of colostomy bags on a cruise ship is not a problem. You can always request yellow medical waste bags, which will be regularly and discretely collected from your cabin.

And finally...
A big Thank You to Virginia Ironside, the writer, journalist, and former agony aunt. I was there at her one-woman show,"The Virginia Monologues: Why it's Great to be Sixty", a fringe production at the Edinburgh Festival when she told the audience that she'd had her colon removed. In the stunned silence that followed she went on to explain that she now wears a stoma bag. This is what we need, more ostomates, especially those in the limelight, to hold up their hands to be counted, so that bowels and colostomies are no longer something we don't talk about.

Rosemary Brierley
Associate Editor

If you would like to contribute to the above debate or have any other issues you would like raised in this column please e-mail:
associate-editor@colostomyassociation.org.uk
or write to:
Associate Editor, Tidings, Colostomy Association, 2 London Court, East Street, Reading, Berkshire. RG1 4QL

Comfort,
Security
& Discretion.

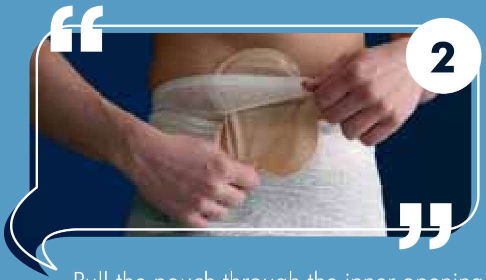
We’ve got it all wrapped up.

carefix™
Stoma Support Garment

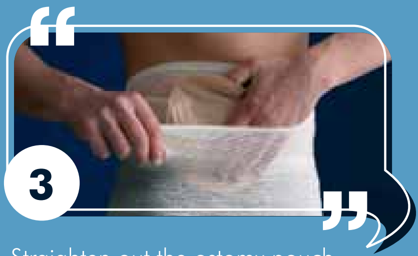
CareFix™ StomaSafe is designed to support as well as to cover an ostomy pouch. Made of a fabric that is comfortable to wear and non irritating to the skin, it allows the user to live an active life by reducing content noise and movement.

It is easy to pull on, safe and convenient for night time use and now available as a completely FREE sample from Bullen Healthcare.

Pull on the CareFix™ StomaSafe support garment.



Pull the pouch through the inner opening.



Straighten out the ostomy pouch.
CareFix™ StomaSafe is in place.

When using a drainable pouch position its opening through the lower opening of the support garment.

- Easy to pull on and easy to use.
- Extra support for peace of mind.
- Reduces content noise.
- Provides extra security during movement.
- Safe and convenient for night time use.
- Works with drainable and closed pouches.
- Inner pocket with stoma opening.
- Lightweight and comfortable to wear.
- Non-irritating to the skin.
- Washable at 60°.
- Stretchy, but latex free.
- Bottom drainage opening.
- Soft and stretchy material.

SIZES (*hip measurements)

S Small: 80-100cm* (31.5″–39.5″*)	**L Large:** 105-130cm* (41.5″–51″*)
M Medium: 95-115cm* (37.5″–45.5″*)	**XL Extra Large:** 115-145cm* (45.5″–57″*)

	Script	/ Pip Codes
Small	CF - S	343-1285
Medium	CF - M	343-1293
Large	CF - L	343-1301
Extra Large	CF -XL	343-1319

SAMPLE HOTLINE
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Colostomy Association Open Day 2009

Reaching out Building awareness Moving forward

The Colostomy Association is delighted to announce the launch of a new venture – our very own Patient Open Days. A pilot day was held during September at the prestigious Liberty Stadium, Swansea.

Patient Open Days are part of the continued development programme of the Association and will be taken to different regions of the UK, the focus - reaching out to ostomates their families and carers, building awareness of the work of the charity and moving the Colostomy Association forward.

Those attending will gain an increased knowledge about their stoma via workshops and talks on the day. Learn more about stoma care and have time to discuss problems or issues that affect them via questions from the floor or if more appropriate in person with a stoma care nurse. There will also be exhibitors - manufacturers and suppliers of stoma care products and accessories, not to mention a very warm welcome from the Trustees and Staff of the Colostomy Association!

About the Day...

Proceedings began at 1.10pm with an introduction from Monty Taylor, Chairman of the Colostomy Association.

Sue Hatton, Executive Trustee, then extended a warm welcome to everyone and thanked the fifteen representatives from manufacturers and suppliers of stoma appliances and accessories and the Urostomy Association for their support. Sue also presented flowers to Maureen Kelly-Smith from SecuriCare and to Jane Wood for their tireless work in organising the event.

Sue expressed her gratitude to the day's speakers: Duncan Wells for providing the colostomate's perspective, Ann Leppington-Clarke, Amanda Gunning and Wendy Osbourne for sharing their expertise as stoma care nurses and Siobhan Crowther and Caroline Meakes for telling us about their work raising awareness through Lynn's bowel cancer campaign. The Colostomy Association was also proud to announce that the final event of the day would be a performance by the Swansea Male Voice Choir.

Sue then handed over to Jackie Dudley, Trustee and head office volunteer, who was to be the Open Day Master of Ceremonies.

The following are a few snapshots from the days agenda. We hope they give you a flavour of the content of the talks and workshops...

A Patient's Story – Duncan Wells Just a Sharp Scratch

When colostomate Duncan Wells spoke at the first session of the Swansea Open Day his voice was somehow familiar. Not surprising really as he is one of the UK's top Radio and Television voiceover artists: his is the voice behind the Daily Mail campaigns, Renault, Nescafe, Kelloggs...and much more.

Regular readers may remember Duncan's story about how he came to have a stoma from "Pathways to a Colostomy" in Tidings Issue 12.

Duncan began by showing a recording of an interview he gave for the television programme, London Tonight. It included film footage of the moment when the faulty flare exploded inside his abdomen! That day Duncan, who is also a Royal Yachting Association Instructor, was at his sailing school in Buckinghamshire demonstrating safety flares for a distance learning DVD. When the TV clip finished he looked around the audience and said, ‘Something meant to save my life nearly took it!’

Doctors told Sally, his wife, that he was unlikely to live for more than a couple of days. Now the medical profession agree that, given the magnitude of the initial injury – the magnesium and strontium compound inside the warning flare burns at a temperature of 3000C – and the following complications, Duncan has survived the unsurvivable.

During Duncan’s nine month stay in hospital, (four months of which Duncan lay in Intensive Care) his spleen, part of his pancreas and some of his small intestine were removed. At one point the surgeons had three ends of intestine and had to decide which two went together! All that remains of his large bowel is seven inches and this now ends in a stoma. Duncan admits, ‘These were dark days and many tears were shed…tears of gratitude, frustration and pain.’

Then at the end of 2006 the time came to go home. There was still some doubt whether Duncan’s intestines would cope with food, so he was still fed directly into the blood stream by a process called Total Parenteral Nutrition (TPN). Then after nine months of not eating, Duncan began very slowly and carefully to try small amounts of food. His intestines began to absorb this nourishment…and his stoma started to work.

Vital to his rehabilitation was Duncan’s need to work and earn money. He is back doing voiceovers and writes a column for Sailing Today magazine. And in his spare time he and Sally have raised over £54,000 - more than enough to pay for the ventilator to say thank you to Wrexham Park Hospital.

Duncan ended his talk by considering self esteem and how he copes with everyday life with a stoma. There were many nods in the audience.

Duncan has lots more up his sleeve and we look forward to hearing from him again very soon.

Facts and Challenges related to living with your stoma

The first part of this presentation was by Amanda Gunning, Clinical Nurse Specialist for CliniMed. Amanda gave us the facts about stomas: why they are formed, the three different types, whether they are temporary or permanent and the various appliances and management options.

There are a wide variety of conditions which may lead to a stoma, including cancer, blockage, Crohn’s disease, ulcerative colitis, diverticular disease, injury, birth abnormalities, incontinence or constipation.

Stomas involving the bowel are most common with an estimated 50,000 people in the UK with a colostomy and 20,000 with an ileostomy. 12,000 colostomies and 6,500 ileostomies are formed each year, but many of these will be reversed. About 10,000 people in the UK will have had their bladder removed and a urostomy formed and about 2,300 operations of this type are performed annually.

Colostomy and Ileostomy - These can be either permanent or temporary. Where the diseased portion of the bowel has been removed and the part that remains cannot be joined together the stoma is permanent. This is normally an end stoma. A temporary stoma may be formed to allow the bowel to recover after surgery or a diseased section to rest. A loop stoma is usually temporary and may be reversed after a period of time which may vary from six weeks to several years.

An ileostomy is an opening arising from the small bowel (ileum) and is usually found on the right hand side of the abdomen. The output from an ileostomy is fairly loose, similar to thick soup or porridge, and most ileostomates find it easier to use a drainable bag which is emptied four or five times a day.

A colostomy is an opening from the large bowel (colon) and is usually positioned on the left. The output tends to be soft and firm and most colostomates use a closed bag which they usually change twice a day.

Urostomy - A urostomy is always permanent. As approximately 1.5 litres of urine is produced every day, the bag needs to be emptied regularly so has a tap or bung at the bottom. A special overnight drainage system is often used while in bed. As the stoma is formed using a segment of small bowel (ileum) urine output can contain mucus.

Stoma Appliances - An ostomate should be able to choose whichever type of appliance is most suitable for their lifestyle. There are closed bags, which are removed and discarded, also drainable bags which are emptied into the toilet then re-sealed. Both of these can be either one piece, where there is an integral flange and the whole appliance is removed, or two-piece where the there is a separate flange (base plate) which is left attached to the skin when the pouch is removed. A flushable (toilet disposable) one-piece pouch has been available for some time and another manufacturer has recently introduce a two-piece version.

Irrigation - another management option - This involves flushing the bowel out with water. Some people with an end colostomy find this provides them with greater control over their lives.

A stoma cap may be used in conjunction with irrigation or a plug may be used to seal the stoma for short periods or while swimming or taking part in other sports.

The second part of this presentation, The Challenging Stoma, was given by Wendy Osborne, Clinical Nurse Specialist for Coloplast. She began by saying that the normal stoma is pink and moist with intact peristomal skin. But what if it isn’t? Wendy went on to consider a number of problems an ostomate may encounter including sore skin, hernias and prolapsed or retracted stomas.

Sore Skin - This often occurs when the output from the stoma comes into contact with the skin. It can happen if the hole cut in the flange is larger than the stoma. It is important to check that no skin is left exposed by placing the backing from the flange over the stoma. Trauma due to frequent removal of the flange can also cause soreness, and damaged skin is more prone to infection. Sensitivity to the adhesive is quite rare but if this does occur. Oakmed produce a range of products where the flange is not a hydrocolloid. Persistent sore skin is a problem that needs to assessed by a stoma care nurse.

Diarrhoea - There are a number of reasons why the output from the stoma may become looser than normal. It may be a “tummy bug”, something you’ve eaten or the side effect of a medicine you’re taking. Avoiding fruit and vegetables for a few days might help and eating white bread, rice and pasta can thicken the output. Avoid dehydration by drinking Dioralyte or Lucozade Sport, often called Isotonic drinks. Anti-diarrhoeal medicine i.e. Loperamide is best taken half an hour to an hour before a meal. If diarrhoea persists for more than a couple of days then a stool sample may be required.

Constipation - Not drinking enough fluid or eating insufficient fibre may be the cause. Lack of exercise or the side effects of some medication may also contribute. Advice is therefore to drink eight cups (2 litres) of fluid a day (this includes your usual cups of coffee or tea) and increase the amount of fibre you eat. Fruit juice might help and if possible take more exercise. Laxatives may be required if the stoma has not acted for 72 hours.

Wind - Missing meals or rushed eating may be a cause as can certain types of food or fizzy drinks. An effective filter on the appliance is a must and deodorants, in particular peppermint, can help with odours. Some ostomates have found taking pro-biotic yoghurt to be helpful.

Pancaking - This is a problem mainly encountered by colostomates and is most common immediately after surgery. Altering the consistency of the output by increasing fibre and fluid intake may help. Lubricating gels and oils or stoma bridges can help the motion to drop to the bottom of the bag. It may be worth trying a different pouch, possibly a two-piece.

Parastomal Hernias - A weakness in the abdominal muscle wall around the stoma can lead to this type of hernia. It is a common occurrence, reported in 40% to 60% of ostomates. Surgery is not always an option unless it leads to blockages or a change in the colour of the stoma. If a repair operation is performed there is a high risk of recurrence. Ostomates who have a parastomal hernia are advised to check the size and shape of their stoma regularly. If the hernia makes it difficult to attach a bag, it may be necessary to change to a different appliance or to use accessories. A stoma care nurse can advise on this as well as suggest an appropriate support garment and also provide guidance on lifting and exercise.

Prolapsed and Retracted Stomas - A prolapsed stoma is where a length of bowel protrudes through the stomal opening. If this happens it is best to consult a stoma care nurse who will check that the pouch does not rub against the exposed bowel and may suggest ways to ensure a leak-proof seal around the stoma.

A retracted stoma is where the stoma pulls back below the surface of the abdominal wall. It may appear to be in a dip or crease. This needs to be reviewed by a stoma care nurse as it may be necessary to use products to fill in the creases or to change to a bag with a convex seal.

Bleeding and Granulomas - When cleaning the stoma, it is normal to have blood spots on the tissue.

Granulomas develop as a result of over-healing of damaged skin or the stoma surface (mucosa) possibly due to friction from the bag. If they are constantly bleeding or causing pain they can be treated.

Rectal discharge and rectal pain - It is normal for the rectum to continue to produce mucus, even though a stoma has been formed. It is OK to try to get rid of it while sitting on the toilet, but avoid straining.

Some people experience rectal pain following surgery. The reason for this depends on the operation that was carried out and will need to be discussed with the surgeon or stoma care nurse.

Amanda and Wendy then asked if there were any questions from the floor and Jackie Dudley, our M.C., was on hand with the roving microphone. Here are just a few questions with their answers asked on the day.

Q. Are there any exercises we can do to prevent a hernia developing?

A. Gentle arm and leg exercises would be appropriate, but avoid doing sit-ups.

Q. Are there any particular high fibre cereals that an ostomate should eat?

A. Porridge is the perfect cereal for an ostomate.

Q. What are femoral or inguinal hernias?

A. They occur in the groin, where the bowel protrudes through a small hole in the muscle. They are much easier to repair than parastomal hernias.

Q. What are granulomas and how can they be treated?

A. Granulomas are caused by the mucosa over-healing and look like raised lumps on or around the stoma. They need to be reviewed by a stoma care nurse who may need to re-size the template of your bag and if the granulomas are causing pain and bleeding will discuss treatment options with you.

Between each presentation there was time for a look around the exhibitors displays. Each exhibitor took time to explain their products and to answer queries from attendees.

Colostomy Irrigation: A question of choice and a question of control

Ann Leppington-Clarke RGN, CNS at The Hampshire Clinic, near Basingstoke, gave a very clear presentation about irrigation, explaining what was involved and why some colostomates can irrigate, while for others the method may not be suitable. She described the procedure and highlighted the advantages and disadvantages and ended with a plea to all surgeons and stoma care nurses to offer this option to anybody about to undergo surgery which will result in a permanent colostomy.

Colostomy Irrigation is a method of cleaning the bowel by instilling water via the stoma. It allows colostomates to decide when they wish to evacuate the bowel, thus restoring control.

Irrigation is suitable for those with an end colostomy, who do not have ongoing bowel disease or complications. It is not recommended if you have active Crohn’s disease, are prone to bowel obstructions or have a large hernia. There is a danger of fluid overload in those who have kidney or heart problems.

To use this method, you need to have reasonable eyesight and manual dexterity, the time to do it and uninterrupted access to the bathroom. However, first of all you need to discuss the possibility of irrigation with your surgeon – many of them don’t know about it or forget to mention it to their patients. If the surgeon gives their approval the technique needs to be taught by a stoma care nurse.

Ann had brought along an irrigation kit to show us. Hung on a drip-stand was the reservoir which holds the water to be instilled into the bowel via a long tube ending in a cone which is inserted into the stoma. Ann also showed us the sleeve which is worn around the stoma to convey the output into the toilet.

The procedure should be taught by a trained stoma care nurse, ideally in your own home. Initially it is carried out every 24 hours usually increasing to every 48 hours. In between irrigations a stoma bag should be worn until confident that no unscheduled bowel actions will occur. Then the plug, which when inserted into the stoma swells up to prevent leakage, can be used. To illustrate this Ann showed us one she had "prepared earlier" by soaking it in water. For those who don't fancy the plug, there is always the stoma cap or mini-bag.

The main disadvantage of irrigation is that it takes about an hour to perform, although it can get quicker with experience. The procedure may not suit everyone and if a colostomate is not able or decides not to use this method it should not be regarded as a failure.

However, for those that choose to irrigate it gives control over bowel action, freedom from wearing a bag and choice of timing of bowel activity. This can improve quality of life, help acceptance of a stoma and restore self esteem and confidence.

Ann Leppinton-Clarke concluded her presentation by saying that she knew a seventy-nine year old man who had been irrigating for forty years. However, there are still many colostomates who do not know about this method of colostomy management.

Irrigation should be offered to anybody about to undergo surgery which will result in a permanent colostomy. Colostomates should know before their stoma is formed that irrigation is an option and be able to choose this method if it suits them.

Jackie Dudley, our M.C., was on hand with the roving microphone to take comments about irrigation from colostomates in the audience.

'I have been irrigating for about a year even though I have a hernia.'

'I have been irrigating for twenty years but I do get worried if the output is not what I expect.'

'I find it much easier to sit next to the toilet while irrigating.'

'I find a small projector stand ideal for hanging up the water reservoir.'

'I had never even heard about irrigation until I went to a support group.'

Removing the Misconceptions

- Irrigation is not difficult.
- Well motivated people with a suitable stoma can easily be taught the technique by a trained stoma care nurse.
- Surgeons should be encouraged to promote this idea.
- Equipment is available on prescription.

Lynn's Bowel Cancer Campaign: A workshop about Bowel Cancer - Prevention • The signs • Screening

Siobhan Crowther and Caroline Meakes told us about the work of Lynn's Bowel Cancer Campaign.

Their presentation explained the facts about Bowel Cancer, stating that it is preventable, treatable and curable.

Bowel Cancer is the second commonest cancer in the UK, causing more deaths every year than breast and cervical cancer put together. Around 35,000 people will be diagnosed with bowel cancer this year. Siobhan went on to explain exactly who is at risk from the disease...

- Older People - Like most cancers, it affects us as we get older - 9 out of 10 people who get it are over 50
- Family History - 1 in 10 families is affected and some families have genes which strongly predispose them to bowel cancer, like FAP and HNPCC
- Already had bowel cancer/polyps - you may be at increased risk and should be monitored
- Inflammatory Bowel Disease - ulcerative colitis and Crohn's disease can slightly increase your risk of getting bowel cancer
- Couch Potatoes - People who don't get enough exercise are at increased risk - walking lots and other exercise can decrease risk
- Being Fat - the obese get more bowel cancers - especially men
- Your Diet - Eating lots of red meat, barbequed meats, processed foods, animal fats increase your chances; lots of veg and fruit, wholemeal breads/pastas, can help your body stay healthier
- Smoking and Drinking - heavy beer and spirits drinking is linked to bowel cancer, smoking can also increase your risk

If you would like to learn more about Lynn's Bowel Cancer Campaign why not visit the website:
www.bowelcancer.tv

or write to:
Lynn's Bowel Cancer Campaign
39 Crown Road,Twickenham TW1 1EJ

Sigining off the day with their awesome voices and singing their hearts out were the Swansea Male Voice Choir...

Their programme was superb and there wasn't a dry eye in the house. A wonderful finish to our first Open Day - thank you guys!

An Australian Perspective of Stoma Care

Diana Hayes R.N.
Master of Advanced Nursing Practice (University of Melbourne)
Clinical Nurse Consultant /Stomal Therapy (Credentialled)
Western Health, Melbourne, Australia.

The process in which stoma care appliances and products are distributed and the ways that people with a stoma are supported differs throughout the world. This article discusses the Australian perspective on stoma care and the methods used to ensure that people with a stoma, in Australia, receive their supplies in a timely and efficient manner.

There are approximately 35,000 people in Australia with a stoma. Each major public and private hospital throughout Australia has a Stomal Therapy Nurse employed to assist people in their recovery and rehabilitation. A Stomal Therapy Nurse (STN) is a Registered Nurse who has successfully completed an accredited course in Stomal Therapy Nursing.

The STN works very close to and is considered part of the team of colorectal surgeons. Our role begins prior to surgery with siting of the stoma plus educating and counselling.

Most STNs in Australia work as independent Clinical Nurse Consultants. Some have other clinical portfolios including breast care, continence and/or wound care. We also have community-based STNs who provide follow-up expert care once the person with a stoma is discharged from hospital. A close relationship is formed between the hospital-based and community-based STNs to ensure continuity of care. The professional body in Australia for STNs is the Australian Association of Stomal Therapy Nurses (AASTN). We have conferences biennially and a professional journal titled the Journal of Stomal Therapy Australia (JSTA). We also have state branches of the AASTN with meetings and stoma-related activities. Because STNs work mostly alone, we have a very close and supportive network across the country.

The system in which stoma appliances and products are distributed in Australia differs to other countries. Australia has a scheme called the Stoma Appliance Scheme (SAS). The SAS is subsidised by the Australian Government - Department of Health and Ageing. In order to ensure that appliances on the scheme meet with the needs of each person with a stoma, a panel was established in 2002. The panel is known as the Stoma Products Assessment Panel (SPAP) and consists of a representative from the Department of Health and Ageing (chair), three representatives from the Australian Association of Stomal Therapy Nurses (AASTN), two representatives from the Australian Council of Stoma Associations (ACSA) and one representative from the Medical Industry Association of Australia (MIAA). The panel meets twice a year in Canberra, Australia's capital city. Communication by teleconference and emails throughout the year also transpire. There is no charge for items on the SAS for people who are Australian residents. However, there are strict guidelines as to how the appliances are acquired and the amount allowed per month.

With the help of their STN, each person with a stoma is registered with a stoma association and they become a member. There are twenty-two associations within Australia. Victoria has the most associations with eight throughout the state. Volunteers mostly manage the associations. Members pay a small annual membership fee and postage money. The appliances can also be collected in person.

The appliances and products that are on the SAS include pouches, removal and protective wipes and sprays, seals, belts, powders, paste and also hernia prevention and support garments. Each product is categorised and the allowance is limited to one type of product per category. There are also maximum allowances on each product. For example, a one-piece closed pouch has a monthly allowance of ninety. However, if more are required, an application for additional stoma supplies certificate is completed and forwarded to the appropriate association. Only a doctor or STN has the authority to complete a certificate for extra supplies. Certificates last for a maximum of six months. This to encourage people with a stoma to have a check-up with their STN or doctor, especially if on-going extra supplies are required. Another interesting factor about stoma supplies is that all stoma appliances that are used in Australia are manufactured overseas. Because of our relatively low population, the companies need to import their products here. Each stoma appliance company or distributor has offices and an executive team. Most head offices are based in Melbourne, Victoria. Each company has one or more territory manager who visits the STNs and associations to provide educational and professional support. Each company supplies a discharge kit, which is ordered by the STN. This is to ensure that the patients are discharged home with some supplies prior to receiving their first full month's supply.

Members are kept informed and are able to network via their own journal called Ostomy Australia. As with `Tidings', our members' journal has a forum for seeking professional advice from an STN. As well as associations we also have stoma support groups throughout the country.

Australia has a unique scheme for providing and distributing appliances, however, the needs of the person with a stoma, are universal. The Australian Government supplies the stoma appliances to all Australian residents who have a stoma, via the associations, and the STNs provide expert professional care and support. In this regard, we really are a lucky country.

About the author:

Diana Hayes works full time as a Stomal Therapy Nurse at Western Health, a major teaching hospital network in Melbourne. She is a member of the Stoma Products Assessment Panel (SPAP) and was the editor of JSTA for two years. Diana has her own publications including "The Stoma Care Manual: A Practical Guide for People with a Stoma" and "Nutrition for People with an Ileostomy".

Pathways to a colostomy

An interview with Christopher Done

Christopher was born with Hirschsprung's disease, a condition named after Harold Hirschsprung who first described it in 1886. It occurs in 1 in 5,000 births and is more common in boys than girls.

Reader PANEL contributor

Chris first contacted the Colostomy Association because he wanted to help raise awareness about the work of the CA offering to fundraise by running in events. He visited the Reading offices in March this year for a chat. Tidings talked to Chris about his experiences of living with a colostomy and his own personal journey of how he came to be a colostomate. This is his story...

Chris was born in Nantwich Hospital in 1967, the youngest of twin boys - he also has two sisters, one older and one younger. Living with Hirschsprung's disease was difficult for all the family: There were many visits to his G.P. and the Royal Manchester Children's' Hospital.

As a child Chris had to have regular rectal wash-outs and one doctor tried electrical stimulation treatments to get his sphincter muscles to work. At primary school faecal soiling was a real problem and he had to wear pads, which were very difficult to manage. Bowel problems can undermine a child's self-esteem, confidence and progress at school. They can lead to isolation and situations where they are the 'butt of jokes'. Chris was lucky that he had really good friends around and says, 'If anyone gave me a hard time my mates were there supporting me.' He was often poorly and also missed a great deal of school due to this and because of G.P. and hospital appointments.

At secondary school things didn't get much better and Chris had a great deal of time off because of constipation – he remembers bad wind and much stomach rubbing. He would end up in hospital for a couple of weeks every year for bowel wash outs and enemas.

The one thing Chris really did enjoy was sport, but because he couldn't control his bowels it was difficult to really concentrate on this or other schoolwork. Today, with careful planning and support from teachers and other staff, school can be a successful and happy time. The most important thing for parents of children with Hirschsprung's disease is to be prepared, and to enlist help from others.

When he left school Chris joined a Y.T.S. programme to learn painting and decorating. It went well and he learned to cope day to day but, after much thought, decided to ask if he could have a colostomy. His G.P. referred him to a specialist and he got the thumbs up.

Chris was seventeen years old when he had his colostomy formed at the Royal Manchester Children's Hospital. In the early days he had a lot of wind but that soon calmed down. The stoma care nurse had already shown him a few products and how to fit and change the bag. On discharge from hospital he got into the swing of living with his stoma but after a while had trouble with the filter. Chris says, 'It used to get clogged up and smell.' The stoma nurse suggested he changed to a two-piece system with a closed bag.

His next job was working shifts for a plastics manufacturer and he stayed there for about seventeen years. He was lucky to have a good manager and Chris says, 'If there were any problems he would always give me time in the bathroom to sort myself out.' When he was twenty-seven his stoma prolapsed and he had to have it refashioned. He was in Leighton Hospital for about a week and all went well.

Suzanne and Chris have been married for sixteen years and have a little girl called Jessica. He is still keen on sport: an avid Leeds supporter and goes to all their matches at home and away. There have been no bad experiences with his stoma during matches or on the journey there and back. He says, 'I have a travel certificate and I manage well - you just have to get on with life!'

Chris now works for Tesco. He says, 'It's a physical job but I enjoy it. My colleagues know about my colostomy. They do crack the odd joke, but I know they don't mean any harm. They're a good bunch.'

When he found he was putting on weight around his midriff, Chris knew he had to do something about it, especially as it was causing problems with the filter on his bag. Sport was the answer: he started running to get himself fit, first on his own and then with Vale Royal Running Club. 'Even though you have a colostomy you can enjoy the physical side of life,' says Chris.

Chris also mentioned a product that he was having difficulty tracking down. He wanted a replacement for a protective shield/belt he wore when running. He had obtained his current one from an open day he had attended way back and didn't know where to find another. The girls at the CA offices were able to supply Chris with all the information he needed.

What is **Hirschsprung's disease...**

Hirschsprung's disease occurs where ganglions (nerve cells) are absent in part of the bowel. The bowel is a long tube coiled around inside the abdomen and motions are moved along it by a process called peristalsis. This involves the alternate contraction and relaxation of muscles in the bowel wall. The absence of ganglions means that although the bowel can contract to push the motion it can't relax to allow it to move forward. This leads to pain, constipation and blockage.

The rectum and lower part of the large bowel (sigmoid colon) are the areas most often affected but it can in some cases extend to the whole colon and in rare instances the small intestine (ileum) as well. It is often diagnosed in the newborn when meconium (the sticky black substance that lines a developing baby's bowel during pregnancy) is not passed out through the anus during the first 24 to 48 hours. However, some cases go undiagnosed until early childhood, but there is usually a history of bowel problems and constipation.

Treatment involves surgery where the affected part of the bowel is removed. This may be performed in stages with a temporary colostomy (or ileostomy) formed to allow time for the colon to recover. In some cases the stoma may be permanent.

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

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

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

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

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

Hirschsprung's disease...sources of information and support...

• Hirschsprung's & Motility Disorders Support Network (HMDSN)
The Willows, Forest Road
Narborough, Leicestershire
LE19 3LD

A group of ordinary people and families, whose children suffer from Hirschsprung's Disease and other gastrointestinal motility disorders. HMDSN also offers a group specifically for adults with motility disorders.

Contact: Gerry McGregor
Email: gerry@hirschsprungs.info
Web: www.hirschsprungs.info

• Hirschsprung's Disease UK
This website, formed by Penny Hawkins whose son was diagnosed with Hirschsprung's disease at birth, aims to raise awareness and offer support for people with this condition and their families.

Email:
enquiries@hirschsprungdisease.co.uk
Web: www.hirschsprungdisease.co.uk/

• Core
Freepost LON4268
London NW1 0YT
A charity that funds research into gut, liver, intestinal and bowel illnesses. A leaflet on Hirschsprung's Disease is available by post or on line.

Phone: 020 7486 0341
Email: info@corecharity.org.uk
Web: www.corecharity.org.uk

• Bowel Group for Kids Inc
PO Box 40
Oakdale
NSW 2570

Email enquiries@bgk.org.au
Web www.bgk.org.au

Readers' writes

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

Dear Editor...

Thank you for sending me your Tidings magazine. I have found it most interesting and also very comforting to read about others who have the same problems and feelings about stomas.

Apologies for errors, etc., but this is a very old machine and my fingers are not as nimble as they were. I am eighty-five and have had several setbacks (health-wise) during the last ten years but this operation was the big one for me. I did not have cancer, but various bowel ailments. Anyway, after nearly a year I am getting used to the stoma, in spite of losing a lot of weight…and hair!

As with so many other people I read about in your magazine, my main worry is leakage. I have had two "near misses" lately, which has resulted in a bout of nerves and being afraid to go out. As so many others say, toilet facilities are poor (they certainly are in this neck of the woods.) Last week I just managed to get to the toilets on the front at Lee-on-Solent and used my RADAR key (such a boon), but there were no amenities and it was rather grimy and unkempt. I'm afraid that these days I do not have a lot of energy to explore new avenues and try different aids (sounds lazy doesn't it?). However, I do the usual chores (with reluctant help from my husband!) and still enjoy cooking but, alas, without the wine and the garlic these days.

I'm sorry this letter is all about me and I don't suppose it has helped any of your readers, except to say we must all soldier on and try to cope as best we can – there are so many people with far worse things than our stomas.

Again, many thanks for your magazine and also the free samples. We can only do our best to cope in the way that seems to suit us

Kind regards,
E. P. (Mrs)

P.S. At times it is a bit hard to take the attitude of some people who you can see thinking that there's something not quite nice about our condition!

P.P.S. I wish we could contribute to your excellent service, but being pensioners we are on a rather restricted income.

From Ed: This star letter was written using a traditional typewriter and wins a £20.00 gift card from M&S

Readers' writes

Dear Tidings,

Tommee Tippee takes a dive...

I had my operation in March 2007 and would like to say how very much I appreciate your magazine. It seems that each issue contains an article or reader's comments or experience relating to my condition. I really feel that every person who has a colostomy, for whatever reason, would benefit from receiving a copy when they leave hospital.

Before my operation I went swimming three times a week at the local leisure centre, averaging thirty-two lengths each time. I was feeling really healthy when diagnosed with bowel cancer, so it came as a real shock. I felt I would never be able to get back to the same standard as before my operation but now I am glad to say I am swimming five times a week and again averaging thirty-two lengths each time. I thought this information might encourage others to either take up swimming or get back to it and not let age deter them as I am now seventy-six years old.

Some months ago I read about Tommee Tippee Nappy wrapper in the magazine which I promptly purchased and have been very pleased with. However, I have now switched to FreeStyle Vie flushable pouches which I am finding very good, so my Tommee Tippee is going to be redundant. It is good when out or visiting to just drop the inner bag into the toilet. The name FreeStyle is very appropriate.

I was interested to read in the summer Tidings of the person having problems with her underwear not being deep enough to cover her bag. I have some high-waisted ones provided through my supplier which are perfect.

I just thought you might like to include some of these comments in a future issue of Tidings.

Yours sincerely
S.M. (Ms)

Editor's note
Re: Tommee Tippee, The Sangenic Nappy Disposal Unit. Another reader e-mailed us to let us know that when he purchased this product on-line from Mothercare he was charged £32.99, not £19.99 quoted as the usual retail price in our last issue of Tidings. He also points out that the bin requires cartridges containing the polythene in which the refuse is wrapped up. He purchased a box of three cartridges for £9.99, but again prices may vary.

Hi,

Helpful hints to make a disabled toilet more stoma friendly...

I am property steward of a small church. One of our members has just had to have a colostomy and it will be permanent. Do you have any helpful tips on what I can do to make our disabled toilet more stoma friendly i.e. shelves or anything else you think would help. I would like to get it sorted as soon as possible before our friend returns to church.

Best wishes
J.

Editor's Reply
It is good to know that you are so concerned and understanding about the needs of those of us who have a colostomy. Yes a shelf to lay out a stoma appliance and accessories would be very useful. A hook behind the door for hanging a coat or any other item of clothing which an ostomate might need to remove would also be a good idea. Some ostomates find it easier to change an appliance by looking in a mirror. This would need to be places at waist height. I assume that as it is a disabled toilet there will be hand washing facilities and a bin for disposing of medical waste.

Dear Editor

Is this a record?

I have meant to write before because I thought it would be of interest to your readers to know that I have had my colostomy for seventy-four years plus, in fact, all my life.

The original colostomy was formed at St Marks Hospital, London after a preliminary operation at birth at Torbay Hospital in 1935. I have seen many improvements over the years. Unfortunately reliable appliances were not available during my childhood or teens…many traumatic events occurred in those days! However, I believe that it must be far worse in the beginning if the operation is performed in later life.

Over the years I have had several procedures and operations, including other abdominal complications. In spite of all this I have led an almost normal adult life and been physically very active in work and sporting activities.

The appliances that are available today are very effective and for the last ten years I have irrigated, which is probably the best step of all, although I appreciate not everyone can do this. Socially having a stoma is not the best of disabilities to contend with, but it is by no means the worst. Life can, in fact, be lived to the full.

Yours sincerely
D.J.B. (Mr)

Readers' writes

Dear Editor,

In 2007 I had an end colostomy formed after the removal of a cancerous tumour in the lower bowel. I feel two years is a good trial time and I would now like to let others know that life can be very good after such an operation.

The initial radio and chemotherapy including the daily fifty mile round trip for six weeks was very draining. However, it was made bearable by the body massages provided at the hospital which uplifted both body and soul. After the operation I was introduced to the most marvellous colorectal nurse who "got me going". On leaving hospital she gave me a file of information including a copy of Tidings which, when I got round to wanting to read, I found most interesting.

A few weeks after leaving hospital I developed terrible problems with sore and raw skin around the stoma. For several weeks I attached pouches with micropore tape and waited for the skin to heal. Then I tried several different makes of pouch and had great success with Salts two-piece with hydrocoloid adhesive – no more sore skin.

Slowly the travelling bug returned and my postponed 2007 Falklands trip seemed feasible in 2008. I had developed a fair sized parastomal hernia and it was suggested another year would put me in a better position health-wise. However, by now I was seventy-nine and felt I could not keep hanging about – neither the colostomy nor the hernia was going to disappear. So exactly a year after the operation I set off for the Falklands armed with plenty of supplies in my fourteen kilo luggage allowance – the oldest in a group of six. It was a marvellous trip.

On my return I decided flushable pouches would be even better for future travels. I now use the Welland one-piece and the Dansac two-piece flushable. Both are marvellous. I have tried them both out in Poland, Spain and Italy with great success and no skin problems.

I'm now ready for a month in Australia to celebrate my 80th birthday last May. My energy levels are not sparkling, but my blood tests say I'm all clear. I made up my mind from the beginning that the colostomy plus hernia are now part of my life. My mother had a colostomy as a result of diverticulitis at my age and my brother has had an ileostomy for fifteen years due to Crohn's disease.

My motto for life now is "have bag will travel". It's worked well so far. I think what I'm trying to say is if we can accept the abnormal as normal and make it fit in with our lives and not the other way round, life can be good. I'm very lucky

Yours sincerely
P.G. (Ms)

Dear Editor

Life saver - my Gucci bag...

I would like to share with you and other Tidings readers my experiences of colostomy surgery. On Monday 17 March 2008 I was admitted to the Singleton Hospital, Swansea for emergency surgery for a ruptured colon. I discovered later that I had diverticular disease which is rare in someone so young. I am only forty-three.

After having a three hour operation I awoke in the intensive care unit, to discover a colostomy bag attached to my left side! The surgeon explained this was necessary as it saved my life because my abdomen was full of faecal matter and infection which would have poisoned me if he hadn't operated when he did.

I was told then that it was only temporary - even so a colostomy was alien to me. I hadn't even seen a bag or any of the accessories to go with it! Nevertheless the stoma nurses were fantastic: very caring, reassuring and helpful. They showed me everything, how to change the bag, clean the area and generally look after it. I had my colostomy for thirteen months and I befriended it in the end. I even called it my Gucci bag.

On 21 April 2009 I had the reversal operation using keyhole surgery. Initially the surgeon wasn't going to do it that way because it was too risky and can cause leakage. However, it was done in four hours and I am recovering very well and my bowel habits are now normal. This should be encouraging for anyone else who's undecided about a reversal operation.

M.J.E. (Ms)

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

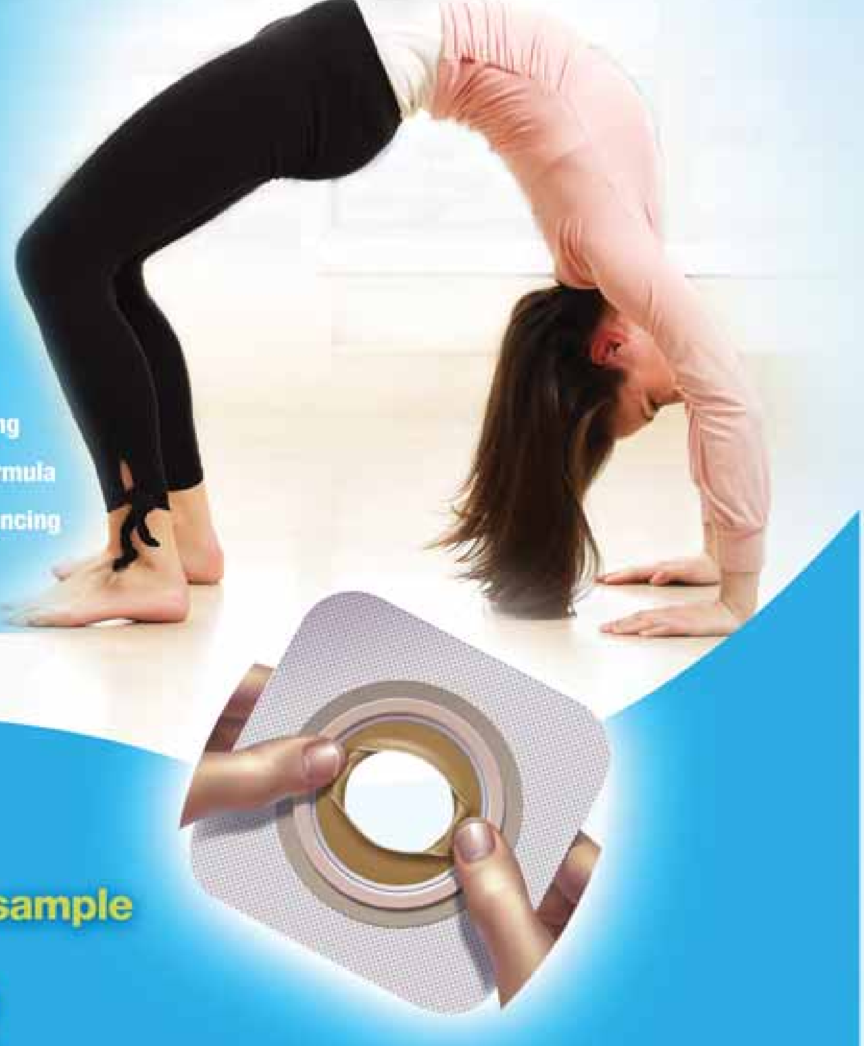
Editing may be required for reasons of clarity or space. In the interests of confidentiality we will publish only your initials and not your full name, unless you give us permission to do so.

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

Reader
PANEL
contributor

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

Yours
Rosemary Brierley
Associate Editor



Me and my hernia

written by Pat Currie

The Association has asked me to write about my recent parastomal hernia repair so here goes. Firstly, a little bit about where it all began...

My name is Pat Currie and I have had a colostomy since 1996. I was very young at the time and everyone felt very sorry for me but not half as sorry as I felt for myself. What a time that was; I never stopped crying for weeks. I had a polyp very low down in my rectum that had become malignant because I ignored all the symptoms, probably for years. I didn't see a doctor for no other reason than embarrassment which seems so stupid now - but hindsight and all that! I do know it is a miracle that I am still here. The cancer was very far advanced. I only recently discovered that and wonder how I would have reacted had I known at the time how slim my chance of survival was…

I manage my colostomy quite well; I irrigate every day, sometimes twice, and plug the stoma. Life apart from that is pretty normal. I work as a practice manager for a very busy medical practice in Liverpool. I have a close and loving family with four grandchildren who keep me busy at weekends.

I developed a small hernia within a few years of having a colostomy. Just my luck. It was operated on but it didn't work and the hernia reappeared and started to get bigger and bigger until it was the size of a half grapefruit. I was always aware of it and thought it so ugly. I am very much an image person, not vain, just lacking in confidence. If I look OK I feel more confident. I would take hours getting ready to go out or to go to work because I never felt comfortable in my clothes and even worse out of them. I really was so self conscious that I didn't go out much and became a bit of a home bird. Shopping for clothes became painful and the latest fashions were mostly ignored unless they could survive the big knickers that were my constant and uncomfortable attire. I would dream about pretty sexy lingerie. I had always loved clothes. Now I always looked lopsided. Funnily enough though, people never noticed until I pointed it out.

Holidays were a problem as I wouldn't go into the pool and my sarong would have to be worn at all times - but hey I was alive and kicking and still got to go on holiday, so let's keep perspective.

I kept thinking about another operation but was scared as I was told it would not be as easy as my first hernia repair because it was so big now. It would be quite a long operation. I thought I would be away from work for months. I was also under the impression that it may not last and I would be back to square one. It all seemed like too much trouble even though I felt quite desperate to look normal. Then I heard of a new procedure. A Teflon coated webbing that was really strong and would help keep everything in place and hopefully last longer.

It still took about two years before I got the courage to see my consultant and ask him if it was going to be such an ordeal. I was really scared and worried that it may not work and I would go through all this for nothing. My surgeon, Mike Scott soon put me at ease. It would be sorted; the operation would take one and a half hours. I would stay in hospital for four to five days. There would be a remarkable improvement in my appearance and I would only be away from work for about 6 weeks. So I wanted to go ahead ASAP.

It was an unpleasant experience to say the least, the cut being the same as the original cut from my resection but at least I still only have that one scar. I was in hospital for five days not a pleasant stay as I was quite ill and in pain. I stayed at my sisters for a further five days and then went home. My tummy was swollen so I didn't see the difference at first. When I did I was ecstatic, no, really ecstatic. I had to take it easy for a few weeks and went back to work with my new body five weeks after the procedure. That was in March, but I think I should have recuperated for a little longer but I am OK.

I can honestly say it was the best decision to go ahead with the procedure and would do it again despite the aggravation. I feel fantastic…I went to Rhodes in April and had a lovely holiday and didn't need a sarong. I still didn't make it into the pool but only because it was too cold. My clothes look good again and my confidence has soared. I would advise anyone to go for it. Get the advice from your consultant; it is so worth having your body back in shape, especially if, like me, your image is so important…I mean I won't go to the shops without my makeup on and my hair washed and blown in place so you can imagine how bad that grapefruit hip affected my life and my confidence…

How can YOU help?

Have **YOU** ever thought about r**aising money for the Colostomy Association?** Fundraising can be very rewarding and you may even find yourself experiencing something new and fun. For us to continue raising awareness and reaching out to Ostomates via CA Open Days, 24 Hour helpline and visiting, we continually have to raise funds - why not give one of the following activities a try!

Get fundraising with our TOP TEN fundraising activities...

1

It's the taking part that counts...

Why not organise a sponsored walk, swim, run, bungee jump, sky dive, dog walk, abseil, treadmill, head shave, hair dye, silence, walk in the park, or baking session.

2

Fingers on the buzzers...

How about a quiz night? You can make this a general entry quiz or tailor the event to fit in with local interest groups.

3

It's all in the bag...

Ask the manager at your local supermarket or store if you could organise a bag-packing event. Get a team together to help pack shopping away and take some money shakers and buckets with you.

4

One lump or two?

You can hold a coffee morning at home, at work, at school, in the community, anywhere! Make lots of coffee (maybe get some cakes in too) and invite friends, family, colleagues and neighbours!

5

Go on, have a guess

How about a simple competition such as guess the name of the cuddly toy or how many sweets in a jar?

6

Spare a little change

Organise a collection at a station or high street; but make sure you get permission from the authorities. Or why not write in ask us to send you our spare change donation box.

7

Have you got the X Factor?

Can you and your friends sing, dance or act? Why not organise a talent night? Or organise a fashion show – you could get in touch with a local college to see if they'd like to be involved.

8

Going once... going twice...

Hold an auction; ask local businesses, celebrities, football clubs or other organisations to donate items. Why not hold an office auction? Bid for a day off, the use of the bosses office or a week of dressing down. Or get everyone to sponsor the boss to work on reception for an hour!

9

Just one click

Make an online donation simply register at www.colostomyassociation.org.uk and follow the procedure it's quick and easy to do.

10

And finally...

Whatever you do, remember to have fun and get everyone you know involved.

Fundraising events are a great way to bring people together!

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...**

Your Donations...

Dear Sir/Madam
I have much pleasure in enclosing cheques in favour of the Colostomy Association totalling £260.
V R W
Harrogate

Dear CA
Instead of presents for my 85th birthday I asked for donations and herewith £50 which you will find useful.
JJ

Thank you everyone for your kind donations

Donations - In memory

Mrs Sari Martin	£120.00
Mrs Teresa Anne Gartland	£50.00

Lucky winners 500 Club

Mrs Russell	£412.00
Mr Broadbridge	£82.40
Mr P Foulger	£82.40
Mr Herpe	£82.40
Anonymous	£41.20
Mrs Richards	£81.40
Mr Leake	£41.20
Mrs Vickers	£20.60
Mr Mansfield	£20.60
Mr Wilson	£20.60

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

Radar keys...don't leave home without yours...

RADAR
the disability network

NATIONAL KEY SCHEME

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

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

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

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

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

Have we got your details correct?

We are updating our records, please could you complete this form if the details we hold are incorrect and return by post to:-

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

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

Name: ____________________

Address: ____________________

____

____

Postcode: ____________________

Tel: ____________________

Email: ____________________

Optional to complete

Date of birth

(day) (month) (year)

Please tick:

☐ **Colostomy**
☐ **Ileostomy**
☐ **Urostomy**

Reason for stoma

Do you Irrigate:

Yes ☐ **N0** ☐

Operation date: / /

Dear Nurse

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

Q: *I am writing to you hoping that you can help me. I had surgery in December 2001 for bowel cancer. My anus was sealed off and a part of my colon also removed. A stoma was formed just below my waistline. Six months later my stoma prolapsed and a hernia also found. The operations were done separately. I had minor problems, until five years later I was taken ill in October 2007. I was continually sick most of the night and the following morning. My wife called our GP who sent me to hospital, I could neither eat or drink. I was put on a drip and sent for x-rays. After three days my condition improved. My bowels moved and I was able to drink. The surgical registrar said that adhesions of scar tissue had caused a blockage. Recently last month the same thing happened again I was really ill when they took me to hospital. I had x-rays. They got me ready for the theatre. At the last minute my bowels erupted and it cleared itself. The surgeon decided not to operate. I was very weak for 3 to 4 days afterwards. Could you please me how to avoid this again. Should I take a regular laxative or avoid certain foods in my diet. I was warned the above trauma could happen again!*

A: Adhesions are scare tissue on the inside of your abdomen following the original surgery and can on occasions cause a blockage of the bowel. Unfortunately these blockages can occur without any warning and there is really nothing you can personally do to prevent them other than keeping yourself as fit as possible by eating well and exercising regularly. This in itself will not prevent the obstructions happening but is obviously good advice for everyone and if in the future you do have this problem again which requires surgery then you will be better able to manage following these suggestions.

Q: *I had an emergency operation 3 years ago to remove a blockage in my bowel, and consequently had a colostomy bag fitted.*
I developed 2 hernias after the operation, and unfortunately, as I have smoked for 60 years, my surgeon cannot operate on them as my lungs are not strong enough. My problem is that just lately, I have had concurrent chest infections, and have been struggling with the most severe, crippling pain from my abdomen area.

I have recently seen my Surgeon and GP. The Surgeon tried to push the hernias back into my stomach, but there is no room as the hernias are so big, and this would in turn push up into my lungs. My GP has given me stronger pain killers, but they make me sick.

Although I am used to the pain from the scar tissue and my hernias, this pain is quite new and incredibly severe, especially when I cough. I have a high pain threshold, but this pain really pushes that to the limit. Can you tell me if you have heard this from anyone else, and if so, what is causing it and is there anything that will help me deal with it.

A: I am sorry to hear that you are having such a painful time with your hernias. Unfortunately hernias can cause pain and discomfort and if the surgeon feels surgery is not appropriate it is a case of trying to manage the problem itself. Obviously pain relief is important and you may need several visits to your GP to find the correct pain relief for yourself. If you find this causes constipation you may require a laxative as well to try to keep the bowels working as the constipation itself can cause more discomfort. To help to manage the parastomal hernia it may be useful to see you Stoma Care Nurse to discuss the possibility of using a made to measure abdominal support. This will not repair the hernia but may help to reduce the pain as it will provide support from the outside to the hernia, therefore relieving the pressure. I hope this helps and you are able to manage the problem better in the future.

Q: *I am the carer for my husband who has Parkinsons Disease and Diabetes. He also had an operation 6 years ago for a blockage which resulted with him having a permanent colostomy. Between us we have coped fairly well but on two occasions recently we had the embarrassment of him having diarrhoea whilst out. I wondered if you could advise us of any precautions we could take in future, e.g. are there large pouches or large* *pants which would help. Any suggestions you could would be much appreciated.*

A: If this loose output is not a regular occurrence it may have been caused by your husbands diet or possibly by a tummy bug he had picked up. If this is the case then it is very difficult to prepare for this occurrence. If, however, the diarrhoea is a regular problem then you may need to look in more detail at what types of food may be causing the problem. Often by keeping a food and bowel action diary you can link a certain food to the loose motion and therefore reduce the amount/frequency of this food or stop eating it altogether. Also if it is a regular occurrence then taking something such as Fybogel, one sachet twice daily with plenty of water, can help to regulate the bowel action. If none of this helps a review by your GP may help to identify if any of your husbands current medication could be the cause of the problem and a slight adjustment in the timing/dose of medication may be needed.

Q: *I have had a colostomy for the last 16 months and will be flying for the first time with it next month. I'm a little anxious about the bag inflating whilst on the flight and wondered if you had any advice. Thank you*

A: Lots of patients find it useful when travelling to use a drainable bag as it is often easier to empty the bag in the plane toilet than trying to change and dispose of it whilst in the air. Also by eating sensibly and regularly for the previous 24 hours, such as avoiding foods and fluids that you know cause you wind, can be helpful. Many patients also ask for an aisle seat on the plane so that it is easier for them to go to the toilet regularly to empty or check the bag. I hope this helps and you enjoy your holiday.

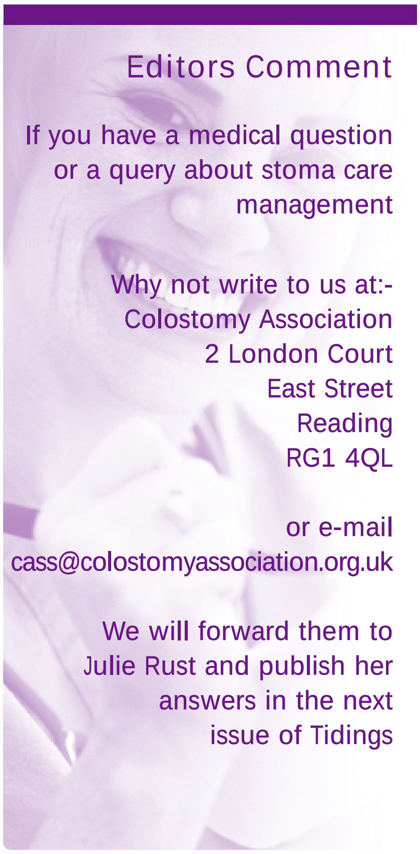
Q: *I work at the a hospital as a cognitive behaviour therapist for people with health anxiety. One of my ladies has an ileostomy for Crohn's disease. Unfortunately she also suffers with hyperhydrosis where she sweats profusely. Consequently this leads to her stoma bag dropping off on a regular basis. This causes her to avoid going out and socialising (and more importantly for her) is the lack of confidence to seek employment. Have you any practical ideas to offer please?*

A This is a problem that I have encountered previously and we had a lot of success using a skin barrier preparation for under the stoma bag. This puts a film on the skin which helps to prevent the sweat from detracting from the adhesive properties of the bag. There are many different ones on the market and your patient's Stoma Care Nurse should be able to get her several samples to enable her to try them and find which works best for her.

Q: *I am registered on your site and I have found it most interesting. I have a stoma bag which is or should be reversed by the end of the year. I had my operation in January this year and since then I have been having chemo treatment. Most of the treatments have gone well apart from the first one when I became dehydrated.*

The worst thing that happens now is that when I have had the fluid injection I always seem to get diarrhoea a few days later. After the injection I am on a course of pills for two weeks and then have one week off. I am on my last course now and due to finish the pills in three days which I am really looking forward to. However, I have had worse diarrhoea this time and really have had a bad time with it, including three leakages, which is not nice. I am taking loperamide tablets for this and have visited the GP who gave me charcoal and codeine phosphate pills, but they do not seem to have helped much. This is really getting me down as previously I was feeling so good.
I just wondered if you had any ideas. I did eat a pork pie one day because I am sick of the rest of the family enjoying some of the food I enjoy occasionally. I also had some leeks and wonder if this is the problem. I also seem to get quite a bit of wind and this causes the bag to fill up with air.
Thank you very much.

A: This may be an accumulative affect from the chemotherapy and hopefully will settle once you have completed your final course. You say your GP has prescribed Imodium and Codeine Phosphate but you do not state what the dosage he has asked you to take or if you have a colostomy or ileostomy. If you have a colostomy you will need to ensure that you do not take too much of these medications as they can then cause constipation. However if it is an ileostomy you have then it is unlikely to cause constipation and you can take up to a maximum of 8 of each of these tablets per day, starting on a low dose and titrating it up until you get a manageable stool consistency. Also if you have a very loose output you will need to ensure you do not get dehydrated by drinking plenty of fluids, possibly using electrolyte replacement fluids. Your GP, Stoma Nurse or Chemotherapy unit should be able to give more precise advice dependant on what chemotherapy drugs you are taking.



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

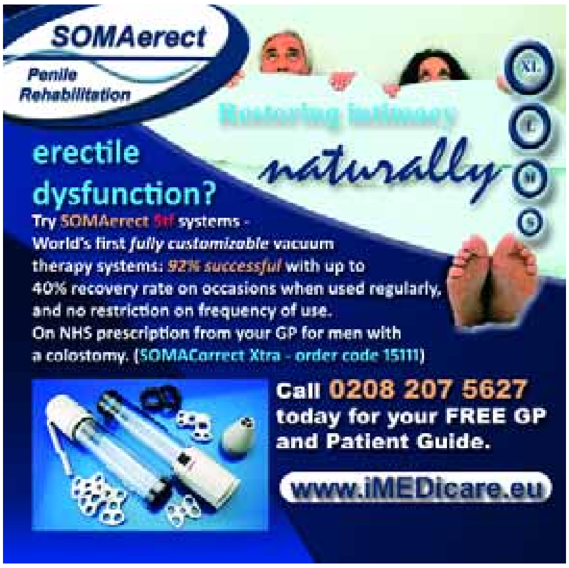
or e-mail
cass@colostomyassociation.org.uk

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

Marketplace

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

If you have anything to sell, an event to advertise or a message to communicate, you can place a small-ad for as little as £20. Please contact the Editor - details and information can be found on page 5. Advertisements received before 28 November 2009 will be considered for inclusion in the next issue of Tidings. So, why not get in touch and let Tidings promote your business or service.



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Telephone:
01205 723327
Linda Butler
(a fellow Ostomate)

DO YOU HAVE A MESSAGE OF SUPPORT...WHY NOT SEND IT IN!

What a support group means to YOU...

C is for caring, compassionate and companionship
O is for obstacles helped to overcome
L is for living and loving each new day
O is for an occasional shoulder to cry on
S is for support, we are ALL as one!
T is for talking to those who share
O is for outlook, the sun still shines
M is for motivate in times of despair
Y is for YOURSELF...we are unchanged

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.

Why not write in and tell us about your support group...


NaturCare
Fragrant
Lightly perfumed
Order Code: 1101A
Breeze
Forest Mint
Order Code: 1103A
Unscented
Maximum Discretion
Order Code: 1100A
Zest
Vibrant Citrus
Order Code: 1102A
The Natural and Discreet Way to Eliminate Odour
50ml

breakaway
putting smiles on young faces

Join us for the 4th Breakaway weekend - May 28th 2010 for three nights at YHA National Forest, East Midlands

We're going back to the forest! YHA National Forest is a modern and eco-friendly building, in Central England. All rooms are 2-4 beds and en-suite. There is also a bar, bistro and Coffee Shop.

Breakaway offers the chance for families and young people to meet, talk about and share their experiences in a relaxed and friendly environment.

There will be stoma nurses on hand to offer support, as well as people who have first hand experience of living with a bowel and/or bladder diversion/dysfunction.

Dietary requirements can be catered for. The cost of 3 nights full board accommodation and activities is just £155 per person.

For more details and booking forms or to enquire about our funding applications please call Julie 07939 690311 or Rachel 07751560013 or alternatively why not visit the Breakaway website: www.breakaway-visit.co.uk

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:
Venue: The Restaurant, Aberystwyth
Park Lodge Hotel, Aberystwyth
Date: 5/11/2009
Time: 11am - 3pm
Salts Healthcare Open Day

Venue: Carwyn James Suite, Llanelli
Scarlets Rugby Club, Llanelli
Date: 10/11/2009
Time: 11am - 3pm
Salts Healthcare Open Day

Venue: Coronation Hall, Ulverston
Date: 11/11/2009
Time: 11am-3pm
Stoma Nurses

Venue: St Georges Hotel, Llandudno,
The Promenade
Date: 10/11/2009
Time: 11am-3pm
Salts Healthcare Open Day

Index: A-Z of Advertisers

Arelle	0800 3893597
B Braun	0800 163007
Bullens	0800 269327
CliniMed	0800 0360100
Coloplast	0800 220622
Convatec	0800 834822
CUIWear	0800 2792050
Dansac	0800 581117
Hollister	0800 521377
iMedicare	0208 207 5627
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

How to contact the Colostomy Association

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

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

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

Helpful Groups & Organisations

Other Ostomy Support Associations...

- IA The Ileostomy and Internal Pouch Support Group
  Freephone: 0800 0184 724
  www.iasupport.org
- UA Urostomy Association
  Tel: 01889 563191
  www.urostomyassociation.org.uk
- IOA International Ostomy Association
  www.ostomyinternational.org
- Gay Ostomates
  Tel: 0845 6436858.
  e-mail info@gayostomates.org
  www.gayostomates.org

Support organisations for medical conditions...

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

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

- National Association for Colitis and Crohn's disease
  Tel: 0845 130 2233
  www.nacc.org.uk
- The Gut Trust
  (Irritable bowel syndrome)
  Tel: 0114 272 3253
  www.theguttrust.org
- Bladder and Bowel Foundation (B&BF)
  Formerly Incontact and Continence Foundation
  General enquiries: 01536 533255
  Web:
  www.bladderandbowelfoundation.org

"The chances are that apart from the contacts you made whilst in hospital you've never met anyone else with a colostomy, support groups change this"...

Glynis Jenkins talks about her support group and introduces us to the Swansea Ostomy Self Help Group

Glynis Jenkins group organiser gives us an insight in to how her group formed, its members and activities...

Swansea Ostomy Self Help Group was formed in 1995 by ostomists for ostomists and is supported by Singleton Hospital. It is a non-medical, non-fundraising group whose objective is to provide a social atmosphere where colostomists, ileostomists and their partners or friends can meet and share experiences and problems.
We currently have a membership of over 70 ostomists, some of whom have been coming to the meetings since its start in 1995.

The group meets in the afternoon, six times a year in Sketty, Swansea and has members who come from as far away as Ammanford and Newport. Although it is a non-medical group, the meetings are sponsored by a manufacturer of ostomy products, who display samples of their product range. This enables the members to see what else is available, keep up-to-date with new products and to order samples to try out. There is a guest speaker at each meeting. Their talks have been on a wide range of subjects, from 'the duties of the Yeomen of the Guard' to 'the history of Swansea street names'.

There is also a very popular Christmas Lunch in December and an "away day" in June. This year, after a morning in the pretty resort of Saundersfoot, we spent an afternoon sampling the wines in Cwm Deri Vineyards. Last year we had a leisurely lunch in glorious weather cruising the Brecon/Monmouthshire Canal.

In the Group we have a variety of home grown talent. We were entertained most spectacularly one Christmas by Ray, the husband of Pam Bennett, one of our members. Ray is a member of a pipe and drum band and he brought part of the band, in full dress, to play at our lunch.

We also have our own "poet laureate" Vince Elward. Vince was a stonemason, sculptor and carver for forty-seven years and his work includes plaques on the second Severn Bridge. He did not start writing poetry until after his operation when he was 73, and has now published several volumes. He said that he had no thought of anyone reading his poetry. It was just a way of relaxing, but has become a major interest to him. He wrote the following especially for the Group...

The Support Group

My friends and I will always search
the way to ease our load,
For load it is, though light for some
and some a rocky road,
We meet together now and then,
to chat and learn to live,
To make each other's pathway
better, we're not afraid to give
Advice to those who need our help,
and take from stronger friends,
For this is how we help ourselves
and tighten up loose ends.

The world of science has done its
best, to give us all a start,
It's up to us to add the zest, to
play a positive part,
For everyone who needs our help,
there's one who's walked that way,
We look for partners every time; we
often hear them say
That "So and So" gave sound
advice, and "So and So" did know,
Amy my new friend is better now,
with thanks to "So and So".

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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.

Stoma support groups in your region...

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

No support group in your area? If there is no support group available in your area - why not set up your own group...

Weigh up the pros and cons and, if you decide to go ahead, find a small group of people to start the group with you, rather than going it alone.

Helpful advice...

- Contact the CA Head Office and they will put you in touch with a volunteer who can help.
- Healthcare professionals may also be able to give some advice.
- Your local library may suggest books for you to read.
- Your local council or voluntary services should also be able to provide help.
- Search the Internet for help and advice.

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

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: Jenny Shaw 01535 652516 or Sue Hall 01535 210483
Dewsbury & District Ostomy
Contact: Janet/Eileen 0844 8118110
Scarborough Stoma Support Group
Contact: Sister Jean Campbell 01723 342388
Rotherham Ostomates Caring Support
Contact: Karen Kilford 078880 575758
CROPS (Colo-rectal ostomy & internal pouch support)
Contact: Gloria 0114 2879503

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

Nottinghamshire:
North Notts Stoma Support Group
Contact: Tore and Nicky Norman
01773 715460
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

Bedfordhire:
Saturday Social Club
Contact: CA for details

Berkshire:
West Berkshire Ostomy Club (WBOC) (Reading)
Contact: Jackie Dudley 01344 426652
Monday Pop In Group (Bracknell)
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
01227 769679
Ashford Stoma Support
Contact: Chairwoman - Ursula Naish
01233 640863


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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

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

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

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

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Account number: Sort code:

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Account name: **C.A. Ltd** Account No: **88781909** Sort code: **60-17-21**

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Signature: **Date:** / / 20

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

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

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

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

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

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

The Association provides:

- advisory literature, written by colostomates and health care professionals.
- a quarterly magazine 'Tidings' especially written for colostomates, their families and their carers.
- a telephone helpline 0800 328 4257 manned 24 hours a day every day.
- over seventy contact volunteers covering the UK, fully trained and experienced, (who are themselves ostomates) these dedicated individuals bring a human touch.
- a volunteer at the request of a stoma care nurse can visit a patient/s before their colostomy surgery, and afterwards in hospital. Home visits can also be arranged.
- attendance at organised stoma care nurses 'open days', that you can visit and where you can learn more about your stoma, in a friendly atmosphere and discuss any problems.
- attendance at manufacturers' and suppliers', 'open days' and exhibitions. This allows us to update you on stoma care products, accessories and services via 'Tidings'.
- a voice for your opinions at on going consultations with the National Health Service and keeps you informed of issues that may affect you.

Here's how **YOU** can continue to support us... simply by making a donation you will ensure our survival

- **Single Donation**
  Single donation from individuals and fundraising events are always welcome and greatly appreciated. So please keep them coming, no matter how small. Just £12.00 (or more) ensures we are able to continue to produce four issues of Tidings per year.
- **Regular Donation**
  Regular donations can be made via standing order (see Donation Form) Regular donations help us to plan ahead and like all donations are vital to our survival.
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- **Legacies - A gift in your will**
  If you are about to make a will, or are considering making a change to your current will, please consider leaving a legacy to the Colostomy Association to help us to continue to offer support to all those with a colostomy.

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

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

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

colostomy association

Office Address: 2 London Court, East Street, Reading RG1 4QL Tel: 0118 939 1537 Helpline: 0800 328 4257
E-mail: cass@colostomyassociation.org.uk Web: www.colostomyassociation.org.uk
Registered Office: 2 London Court, East Street, Reading RG1 4QL
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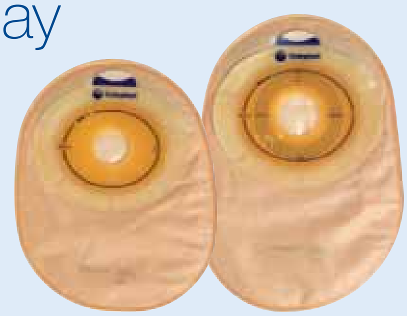

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