

Tidings

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

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colostomy  association



Cover story

- Patient Associations attend Stoma Care Nurses' Conference

Inside

- New Beginnings
- Travel Tips
- Sex and the Stoma
- And all our regular features

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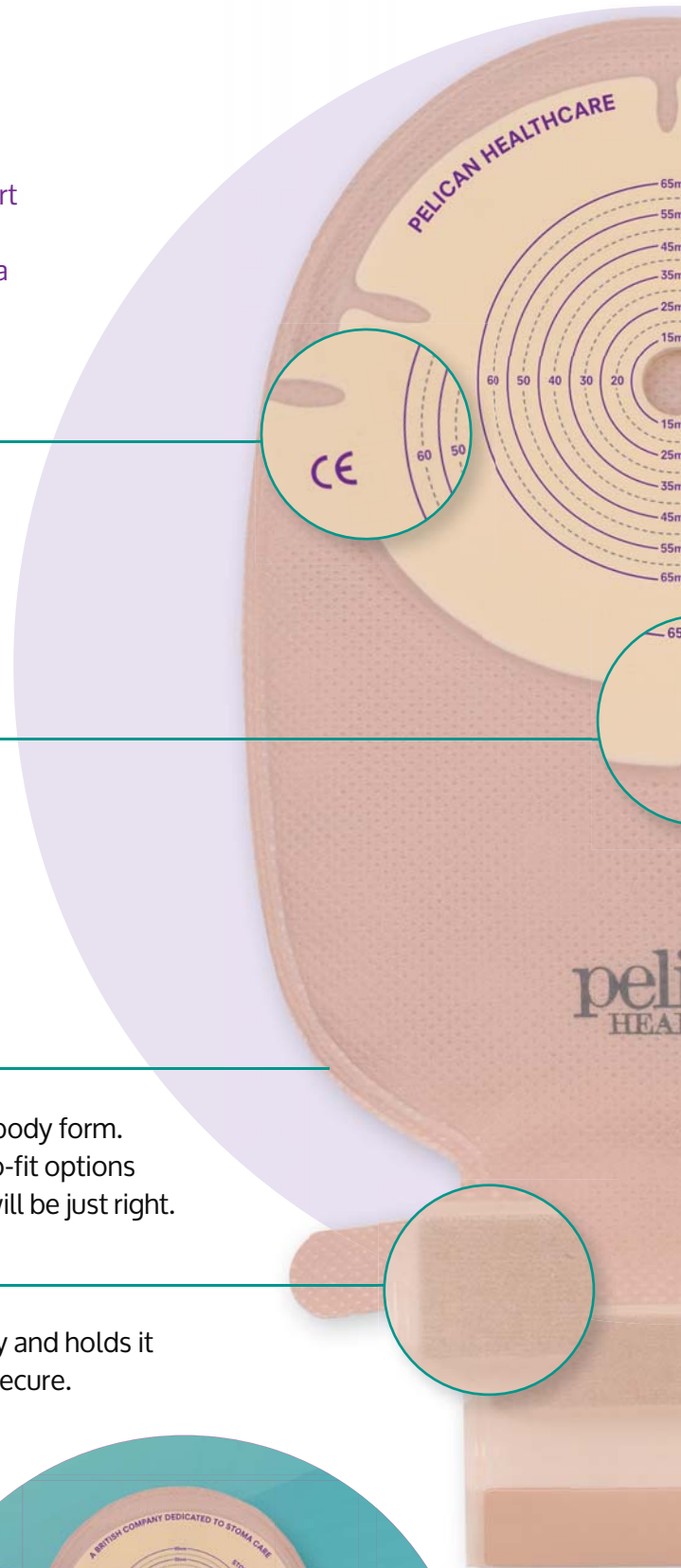
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COVER PICTURE

Left to right:

Sue Hale (CA General Manager), Sarah Squire (CA Trustee), Blake Beckford (ileostomate) and Anne Demmick (IA National Secretary) by the CA stand at the Association of Stoma Care Nurses Conference in Harrogate last October. (See page 36 for full story.)

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dear READERS

Some of you may remember that Issue 1 of *Tidings* was published just after the Colostomy Association was launched in late 2005. It's hard to believe that was almost ten years ago and now it's time to celebrate our 10th anniversary. We do hope you will be able to join us in Reading on the 11th–12th July 2015 at our special events. For more information and a booking form please turn to pages 68 and 69.

When *Tidings* comes through your letterbox it will be the New Year so the theme we have taken for this issue is New Beginnings. We have real life stories from people who when they first had their stoma thought that life as they knew it was over, but later realised it was a new beginning. Farideh writes about how it was hard to accept her stoma, especially when she was told a reversal would not be possible. She felt her life had changed forever but now she goes about her daily life just as she did before – in fact she does more, and she's loving it. In his story, 'You only live twice', James describes how when he looks in the mirror he doesn't see a long scar and a bag he sees a life-saver, a second chance to do the things he's never got around to. In the early days he says that having a reversal was a foregone conclusion, but now six months on he's not so sure that's what he wants and has decided to postpone the decision for another year. Stoma reversal is a subject we are planning to cover in a future issue of *Tidings* and we would like to hear from people who have had this operation. So if you, or anyone you know, have experienced a reversal please contact the editorial team by e-mail or letter.

Maybe for you this is a time for New Year resolutions. If losing weight is on your mind Sophie Medlin explains how, even if we have a stoma, it's still possible to shed

those extra pounds. Or maybe your resolution is to do the things you've been saying you'd do. Solicitor, Rachel Fuller, explains how to make a Lasting Power of Attorney.

The subject of sex was probably not amongst your first thoughts when you were told you were to have a colostomy, or maybe it was something you didn't like to ask about. It may be weeks or months after your surgery before you, or your partner, have questions you'd like to ask, but by then you are no longer seeing your stoma care nurse. Sarah Anderson, a counsellor in relationship and psychosexual therapy and an ostomate herself, writes about Sex and the Stoma. **Colostomy Association** Trustee Trevor Andrews also covers the subject from the male perspective.

The New Year is also the time for making plans – a holiday perhaps. If, as a new ostomate, you have concerns about flying Duncan has advice for a smooth transit through airport security. It is also important to make sure you have sufficient ostomy supplies with you. Brian tells us how irrigation has meant, he can take everything he needs for a 3,000 mile cycling trip around Europe in one pannier on his bike!

As always, we look forward to hearing from you, our readers. Please keep sending us your stories, your comments and suggestions so we can share them through the pages of *Tidings*.

Happy New Year to you all from the editorial team and all the staff at the **Colostomy Association**.

Rosemary Brierley
Chair of Tidings Editorial Team

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

How to become a member of the Colostomy Association

Simply contact us by post:
Colostomy Association
 Enterprise House, 95 London Street
 Reading RG1 4QA

By telephone:
General Enquires: 0118 939 1537

Stoma care queries only:
Freephone Helpline: 0800 328 4257

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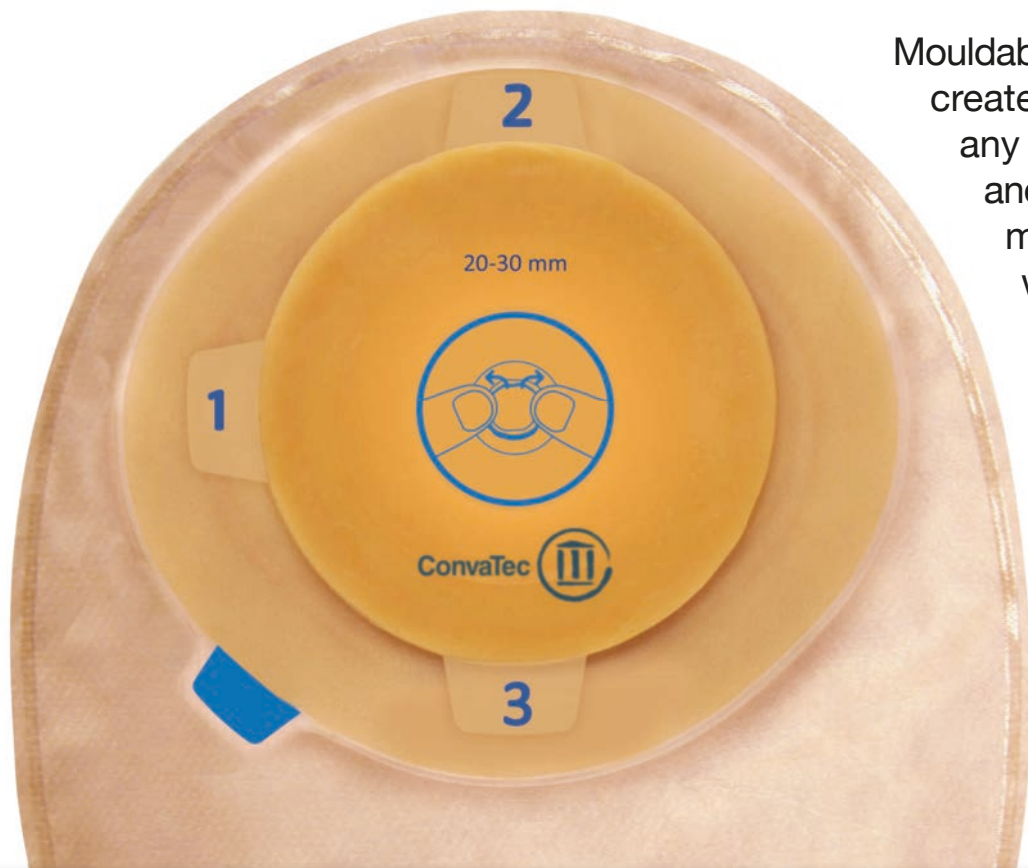
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1. Szewczyk MT, Majewska GM, Cabral MV, Hölzel-Piontek K. Osmose Study: Multinational Evaluation of the Peristomal Condition in Ostomates Using Moldable Skin Barriers. Poster presented at ECET, Paris, France, June 2013.

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Standing ovation...

"..reportedly the only one given in ten years."

On the outside Aled Griffiths looks like any 11 year old boy, cheeky, full of confidence and with a lovely happy smile. The only indication that there may be problems is when you see his hands.

Aled was born in 2003 with VACTERL association. Some of his anomalies include a hole in the heart, imperforate anus, one kidney, spinal defects as well as the hand and arm issues.

He spent the first eight weeks of his life in Southampton general hospital where he had a colostomy formed at two days old followed by open heart surgery at six weeks. As Aled only weighed 4lb 6oz the stoma bag was huge in comparison to his little body.

The next eighteen months were spent visiting hospitals in Plymouth, Southampton, Bristol, and Birmingham to see the various specialists, as well as occupational therapists and physiotherapists that Aled required on a regular basis. It was quite a tiring and emotional time for all the family as the appointments were almost every other day, but we got through it and Aled was thriving with all the attention that he was receiving.

Aled had his colostomy reversed at 11 months old, at which point we hoped that things would be okay with his bowels, but over the next 18 months we realised that things weren't improving. This was confirmed whenever he had an x-ray as it would show an impacted colon. Also from an early age it was noted that he had trouble with his bladder. Subsequent tests showed that he had a neuropathic bladder with a capacity of only 100ml.

Aled's bowel issues were a concern at first, especially with the constant dirty nappies after the reversal. However, once we found out about washouts and started to do them it all started to change. The panic about him not being clean around his friends soon disappeared.

All that was needed now was a way to make it easier for Aled to do them on his own. We hoped that the Peristeen anal irrigation system would allow this but, although the system was great to use, Aled's hands meant that assistance would be needed. At that point his consultant suggested the ACE.

So at the age of seven, Aled was admitted into Bristol children's hospital for an operation known as the ACE procedure. At the same time he was to have a bladder augmentation and a Mitrofanoff procedure.

However, this was complicated due to adhesions from previous bowel surgery. These adhesions meant an emergency trip back to theatre for a seven and a half hour operation. He was finally allowed home after two months, but it would be another two months before he could go back to school. The ACE was exactly what he needed, within 12 months he was fully independent with all his needs.

At the age of eight, Aled was invited by Coloplast to speak at a continence nurse study day, to talk about the Peristeen anal irrigation system which he had been using prior to having an ACE. Aled has always been an outgoing person, talking to anyone that would listen to him, so this event really suited him, especially when he was declared guest of honour. From there he did several presentations to small groups of medical professionals and also at a conference in the USA for people affected by VACTERL association.

In October 2013, when he was ten Aled was invited to speak at the Association of Stoma Care Nurses (ASCN) conference at the Celtic Manor Resort, Newport, South Wales. We were told it would be in front of 200 nurses. However, when we arrived at the conference it was soon evident that it would be to a much larger group, in fact it was to 600 people. Aled gave his presentation as if he had been presenting for years. He was calm, confident and engaging and at the end of his presentation he received a standing ovation, reportedly the only one given in ten years. This conference was to be the start of new things for Aled. He was asked to become the Children's Ambassador for the Mitrofanoff Support group which he accepted and for which he is very proud. So now he spends some of his time sitting on committees advising on children's matters. The rest of his time is split between talking at events and sailing, which he enjoys. He has recently completed the Royal Yachting Association (RYA) junior sailing scheme levels 1, 2 and 3.

Having conduit stomas has really helped in Aled's independence. With a little bit of



planning he can stay overnight with his friends without anyone being aware of his issues.

A last praise for Aled is that even after all his time out of school he has continued to show that he has an academic ability. In September 2014, he took the 11 plus exam which is used as an entrance test to gain entry to the city's only boys' school. He received the results on the 17th of October and cried as he read that he had gained a place at the school.

The **Colostomy Association** has invited Aled to our 10th Anniversary Celebrations in July 2015. He has agreed to take part in the fashion show on the morning of Sunday 12th July and is really looking forward to it.

Medical Terms Explained

ACE (Antegrade Colonic Enema) procedure

An operation where the appendix (or a section of bowel) is brought out through the skin to form a very small conduit stoma. This forms a channel into the bowel which can be catheterised to introduce water and a stimulant to wash out the bowel.

ACE is explained in more detail in *Tidings 35 Page 57*.

Mitrofanoff procedure

An operation where the appendix (or a small section of bowel) is used to create a conduit (channel) leading from the bladder and out through the skin. This forms a continent stoma which has to be catheterised to drain urine from the bladder.

For more information:

Visit: www.mitrofanoffsupport.org.uk

Tel: 01202 937 530

Colostomy Association Awareness Day 2014

In the autumn edition of *Tidings* we briefly touched on the launch of our very own **Colostomy Association Awareness Day** which will take place on the first Saturday of October each year, to complement World Ostomy Day itself.

Various activities took place around the country and it was great to see people embrace the idea. Featured here are some of those who took part:



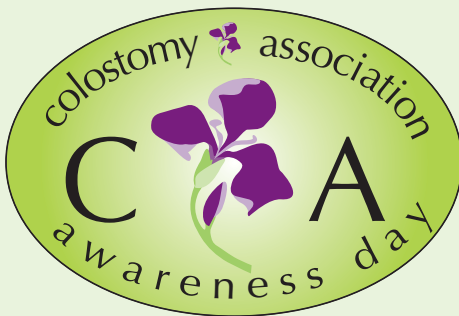
Colostomy Association Volunteer, Farideh is pictured here at the Royal Devon & Exeter Hospital (RD&E) running a stand in their Oasis Restaurant for us. Farideh says: "The stoma care nurses and I ran the stand and we answered questions from the public and the staff. Representatives from Coloplast and Hollister were there introducing their new product. The stand was visited by **Colostomy Association** President, Ian Daniels, the general public and the staff of RD&E. I had the opportunity to talk to a few members of the public and raised awareness on some of the issues faced by people with a stoma."

In Bridport people involved with The Living Tree kindly organised a mini-concert and afternoon tea party for us. This group run a support centre for those affected by cancer, helping them with 'new beginnings'.



Pictured above at Bridport's Quaker Meeting House from left to right are: Fiona Burkman; Jo Millar; Jane Silver-Corren and Jo O'Farrell. There were songs from the *Rising Voices West Choir*, led by choir leader and Bridport town crier Jane Silver-Corren also performed. This was followed by an afternoon tea party and they raised **£90** for the **Colostomy Association**, which was a lovely surprise.

Co-founder Jo Millar said: "With the *Rising Voices West Choir* there's lots of evidence for the benefits of singing in a number of health conditions, but for people recovering from cancer treatment it helps to relax them and gets their lungs going again.



Our mini concert and tea party have been a great success with more than 15 members, enabling us to raise awareness and funds for the **Colostomy Association**. The aim of The Living Tree is to offer friendship, creative activities, holistic therapies and relevant diet and lifestyle information for anyone with any cancer!"

Initial start-up funding for The Living Tree came from Macmillan and other contributors include West Dorset District Council, Dorset Cancer Network, Bridport Carnival, and Brit Valley Rotary. The Living Tree was granted charitable status in February last year.

Group members are at various stages in their experience of cancer – some recently diagnosed, others undergoing treatment, some in remission, and others post-cancer – but the group is open to anyone. Jo says: "People may not know how to handle it when they hear a friend or family member has got cancer but The Living Tree has that understanding. The group helps to really highlight that your life doesn't end because you have cancer, and in many ways it can actually be a new beginning." Anyone interested is welcome to join the group at the Friends Meeting House, South Street on Friday afternoons between 2:00pm and 4:30pm. For more information, visit: www.thelivingtree.org.uk or call Jo O'Farrell on **01308 427 851**.



Meanwhile, **Colostomy Association** Facebooker, Steve Clark drove his taxi-cab around Portsmouth for **several days** to maximise on the opportunity, also obtaining an impressive media presence locally in several newspapers and also raising over **£1,350!** Steve's story features more fully on **page 17** of the magazine.

Thank you so much everyone for all your efforts with our **Colostomy Association** Awareness Day! We're hoping this special day will be an annual feature in the diary of support groups, supporters, hospitals, etc. and become more popular year on year.

Perhaps you could consider running an activity next year for our 10th anniversary celebrations. That would be fantastic!

Other activities which celebrated World Ostomy Day:

Geraldine Howell told all her family, friends and visitors about our range of free services, encouraging them all to leave a donation in a **Colostomy Association** collection box in her hallway.

Geraldine has kindly donated **£100** from this activity after adding in the donations that had been received in her husband's barber shop too!

The Glasgow Stoma Support Group helped to raise stoma awareness on World Stoma Day by running a table in Cumbernauld shopping centre.

Maureen O'Donnell, Chairperson of the group says: "A local charity shop lent us a mannequin on which we put underwear and a stoma bag, which helped to get people's attention.

One man said he had had Crohn's disease for 20 years and was considering getting a stoma to relieve his symptoms. Alan Turnbull, a member of our group, also helped out on the day, and was able to talk about his own journey of Crohn's disease to having an ileostomy.

We had a lot of interest from people who were amazed that you can lead a normal life with a stoma. I think they expected us to have horns!! But hey we all look normal. Others helping out on the day included Marlyn Murray and Isabel McEwan.

The Glasgow Stoma Support Group meet on the first Tuesday of the month. We have a variety of speakers and they all talk about health issues relating to stomas. We also have manufacturers displaying their wares.

At our team meeting on 7 October, some of our members mentioned that they had done something on World Stoma Day to raise awareness. Someone had a teddy with a stoma displayed in their home window and somebody else was on holiday and brought the subject up with fellow holiday makers. While another member told a neighbour or a friend.

Overall, our group did a great deal on the day to further reduce the stigma of having a stoma. I am proud of us all. Roll on next time!" Our thanks go to Maureen and clan for sharing their activities with us. It's much appreciated.



Pictured here: Maureen and Alan of the Glasgow Stoma Support Group



Having fulfilled my first complete year as President, I feel a strong sense of pride in what is being achieved by our wonderful Charity.

This is a very exciting time to be involved with the **Colostomy Association** as we plan for the next decade and beyond.

As a colorectal surgeon I see first-hand the impact of having a stoma on people's lives and I'm always promoting the **Colostomy Association** and its free services to patients and fellow healthcare professionals. I know what a very real difference this support has on people whether they are patients or their friends and family.

Without our dedicated volunteers, the high quality 24 hour support **Colostomy Association** provides would simply not be available to the thousands of ostomates in the UK (and worldwide) who need and use our help. Thank you all so much.

A BIG thank you also goes to the many fundraisers who have undertaken a wide range of activities to make 2014 another successful year – from cycling or running to wearing a purple wig for the first annual **Colostomy Association** Awareness Day. Your efforts are very much appreciated.

This year, we'll be celebrating the 10th anniversary of the **Colostomy Association** as we know and love it today.

Our special celebratory events include an Open Day, fundraising Gala Dinner and Fashion Show and I hope you can join us at the *Royal Berkshire Conference Centre, Madejski Stadium* in Reading over the weekend of 11th-12th July.

I'm looking forward to giving talks on the topic of hernias and to presenting some very special awards. More information about the whole exciting weekend and a booking form can be found on **pages 68 and 69**.

I'm also looking forward to raising the profile of the **Colostomy Association** further to enable us to reach many more ostomates who would benefit from our invaluable support.

Thank you all for making **Colostomy Association** what it is today!

Wishing you all a healthy and happy New Year.

**Ian Daniels FRCS
President
Colostomy Association**

Message from our President



Many of you will remember a time, nearly ten years ago, when McMillan decided that they could no longer finance the then British Colostomy Association and many people believed that this might be the end of a charity which supported colostomates.

However, an enterprising group of volunteers thankfully decided that this must not be allowed to happen and through their incredible initiative and a great deal of hard work, the **Colostomy Association** evolved.

Looking back over the past ten years we are all extremely grateful for their voluntary efforts and proud of where we are today, as a prominent UK charity in the stoma world.

Since 2005 we have twice moved offices and now occupy premises with an excellent training room and superb facilities for staff and volunteers.

Tidings Magazine is a renowned flagship publication for both supporters and stoma professionals and we now run volunteer training programmes, provide a wide range of literature, offer a popular closed Facebook group, attend open days in conjunction with manufacturers and hospitals in most parts of the UK and a number of local support groups have also been set up by several of our dedicated volunteers.

Our 24/7 Helpline has also been a huge success, receiving thousands of calls each year.

None of this would have been possible without the determined efforts of the staff at Head Office and our wonderful team of UK wide volunteers. Our grateful thanks are due to all of them.

In any charity it is important that staff empathise with both volunteers and our supporters and the team at Enterprise House always go the extra mile to ensure that colostomates receive the support they need often at a very vulnerable time.

During 2014 two wonderful Trustees, Jackie Dudley and Duncan Wells, retired and they had contributed enormously to our successes during their time in office. Our thanks are extended to them both for their invaluable endeavours.

Last year also saw the appointment of four new Trustees – Trevor Andrews, Mandy Gunning, Caroline Emeny and Wendy Hetherington – all of whom have been heavily involved with the **Colostomy Association** for many years and they all bring a wealth of skills and experience to our Board of Trustees. We're feeling well equipped to face our onward journey.

We look forward to serving you in 2015 and to seeing you in July. We would also like to take this opportunity to thank you for your ongoing support.

All good wishes for 2015.

**Monty Taylor
Chairman of the Trustees
Colostomy Association**

Message from our Chairman

You Only Live Twice



“..my organs were starting to close down!”

My name is James. I'm 42 years old and live in West Yorkshire with my wife and sixteen year old son. I work for an IT services company and enjoy running and managing a junior football team in my spare time.

This is my story about how one Tuesday morning six months ago I woke up feeling something wasn't quite right. As it turned out, that was quite an understatement! This is my story, one that's taught me so much about myself and life in general.

I woke up around 5am with a very strange pain in my lower stomach. It wasn't a bad pain by any means, more of an uncomfortable feeling; a bout of diarrhoea and sweats followed with frequent visits to the toilet that morning and flu like symptoms. It was also painful to pass urine although I didn't think much of that at the time and suspected I had nothing more than a sickness bug.

By mid-afternoon, the following day my symptoms were generally not improving. Although the diarrhoea had long since stopped, I still felt ill and the pain in my stomach was not subsiding. Being a bloke, I was still reluctant to visit the doctor but, after prompting from my wife, I made an appointment. My temperature was 104 degrees and the doctor immediately sent me to the Medical Assessment Unit at my local hospital. The doctor there saw me after about one hour and said: "I want to find out why a fit, healthy, 41 year old with no medical history has stomach pains and

a high temperature with no obvious signs of what's wrong." I was moved to neighbouring Huddersfield Royal Infirmary that evening.

On Friday, a consultant diagnosed a urine infection and said that two to three days on a course of antibiotics should see me cured and out of hospital. Not long after lunch I got the same urge to go to the toilet as I'd had on the Tuesday morning. However, this time something was different and I felt badly ill. Soon after returning to my bed, I got the most intense pain. Thankfully some painkillers and morphine quickly took the pain away and sedated me. The consultant visited me two hours later and told me that they would need to operate as they suspected appendicitis.

My wife was called back to hospital and as the evening wore on, I edged closer to surgery. I was also in the early stages of sepsis, in other words my organs were starting to close down! As I was taken into the theatre, I remember the anaesthetist giving me a playful pat and a reassuring smile – I must have looked petrified!

Five and a half hours later, I was wheeled back onto the ward and, whilst it was unknown to me at the time, my life had changed forever. The consultant explained that they had found one single diverticula and that my bowel had perforated causing peritonitis. The operation had taken a long time as I was full of poison from the peritonitis. He told me they had performed a Hartmann's procedure and that it could be reversed once my bowel had rested. I'm

glad that I was still partly out of it as the fact I was now wearing a colostomy bag was a lot to take in!

I was in hospital for another seven days, building up my strength. I had a visit from the colorectal nurse three days after my operation. I remember her being really jolly, but frankly I wasn't in the mood as I came to terms with my new body. I had a bag, 34 staples and was feeling like I'd been kicked around the room. What was there to be jolly about? (I've since seen the same nurse at a stoma clinic and she's a lovely, helpful lady. I apologised if I was rude.)

As the days passed I tried to come to terms with things. My bowel was slow to get going (part of the course apparently after a major operation) and for a while the doctors thought I may have a blockage. I remember struggling to get off the bed in the X-ray department and feeling so low on strength. It was a culture shock to someone who was used to being so physically active and reliant on his own strength to do things. One of the low points was a couple of days after the operation when a nurse had to help me shower; it just wasn't me, to need so much help. Looking back, however, I was far more poorly than I realised and that helps fuel the pride of how far I've come.

I was overjoyed to be released from hospital. I felt every bump in the road on my way home, and was very nervous about my first meal. My wife had to walk up the stairs behind me for the first few days in case I lost my balance and fell back down.

REAL LIVES JAMES SHARMAN

As the days went by I started to get to grips with my situation. In hospital, despite the initial shock, I had learnt how to change my bags – simply because they wouldn't let me home until I could. I decided very early on that positivity was the key. As I had time on my hands, I started to get into twitter and followed some very inspiring people and website pages. All in all other ostomates made me realise that having a stoma need not be a barrier to doing anything.

The next three months were a voyage of discovery. I was determined to get out and about as I tried to embrace my new way of life discovering the radar key system and the best places to change. I was given the thumbs up by my consultant to go running again and build up fitness. Life was about coming to terms with my two new best mates – stoma and bag! My stoma started to behave like my bowel did previously and still to this day has a pattern – busy in the morning and quiet (mostly) for the rest of the day. Great for planning! I learnt what food worked for me and what didn't. For example, I was delighted to learn that curry has no adverse effect as I love Indian food but discovered that fish can send my stoma into overdrive.

I returned to work on a part-time basis at first. It was tiring but enjoyable to be back to normal. Since then I have gradually built up my hours and was back full-time six weeks later. I'm still building up to driving long distances (required in my job) but so far so good, including bag changes at work (usually just once in the morning).

One thing I've not mentioned so far is the reversal. My Hartmann's procedure was temporary and the intention was to have my stoma reversed and my bowel reconnected. From day one I've always known that at some point I would have to decide if I wanted to have the reversal operation. In the early days, I had no intention of staying like this; the reversal was a foregone conclusion. However, as I left hospital and started to recover, I realised I could cope and not only survive but prosper. I treated every event on its merits and kept a list of how I could cope with a stoma. My plan was that if each event passed off with no problems then maybe I didn't need the reversal. I can honestly say that there have been few occasions where it has been an issue. Would I have the reversal done? As it stands I am undecided and will make a decision once I've been to see the consultant.

They say what doesn't kill you makes you stronger and it's certainly change my outlook on life, as below.

1. **Treat life as a second chance** – get out and do things that you've wanted to do. I hold a number of voluntary positions

most notably in junior football and as a school governor. I've also recently taken up a number of new activities that I just wouldn't have done had it not been for my new outlook on life.

2. **Stay Positive** – it would be very easy to be negative and be down about what has happened. For example, it would be easy to look in the mirror and see a bag and a long scar but I decided very early on that positivity was the only way. So instead I look in the mirror and see a life-saver. Without my stoma, I wouldn't be here. It's as simple as that. On my phone I have a picture that my wife took of me lying in my hospital bed just a few hours before the operation. I use this picture as an inspiration if anything gets me down or I'm having a tough day at work. It's a reminder that things could have turned out much, much worse!
3. **Enjoy the moment** – it's too easy in life to always look forward to things without actually enjoying what you're doing in the moment. A brush with death certainly makes you appreciate things more, so a conscious effort not to just rush through the week to the weekend for example is the order of the day for me.
4. **Seek Advice** – don't be afraid to ask for assistance. My local stoma nurses at

Calderdale Royal Hospital have been an excellent source of advice.

A number of websites e.g. www.colostomyassociation.org.uk and www.greatcomebacks.com, **Colostomy Association's** closed Facebook and Twitter accounts are also great for advice and staying positive. Until I had my own stoma, I didn't realise how many people had one, the level of inspiration on Twitter is really good, it's a true little community helping each other. People such as Blake Beckford and Bethany Townsend are raising awareness and helping to remove the stigma.

James Sharman

James says he is going to postpone the decision about whether or not to have his stoma reversed for twelve months whilst he considers the best course of action.

In a future issue of *Tidings* we have healthcare professionals writing on the subject of reversal. We are also planning to include patients' experiences. We would therefore like to hear from anyone who has undergone a reversal. How was the operation itself and how did it feel afterwards?



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From One Ostomate to Another

The column where ostomates share their experience of different types of stoma appliances, and pass on their hints and tips.

How a one piece pouch can work well for ostomates who are partially sighted or registered blind

Stoma nurse specialist, Sally Wright, visited a colostomate who was registered blind, yet managing her stoma independently. The patient had contacted the hospital stoma department for help as she was frequently experiencing leaks.

Sally says: "During the visit we talked about the use of different pouches and what she had tried in the past. She showed me how she was managing with her current two-piece product. She found it very fiddly to use, which surprised me as the two-piece click system had always been promoted for patients with limited sight and dexterity issues, due to the audible click. As the use of touch was of more importance to this individual patient rather than sound, the clicking system of the two-piece was more of a hindrance to her.

"I noticed that in applying a pouch to her stoma she tended to insert the tip of a finger of her left hand into the end of her colostomy so she could feel exactly where to apply the pouch. Then she guided the pouch on top of her stoma with her right hand to gain a central position. With the two-piece she could not guide both entities to fit the stoma which resulted in the flange overlapping the stoma and causing leaks.

"As an experiment we tried a simple one piece system. The patient was delighted with just one slim fitting pouch rather than



Fig 1

two pieces of the pouch. She felt she was able to fold the pouch easily with one hand inserting one finger into the aperture from the front of the pouch so as not to touch the adhesive side [Fig 1] whilst at the same time feeling her stoma with the other hand.



Fig 2

"She could then guide the hand holding the pouch towards her stoma and insert the finger from the front of the pouch to the tip of her stoma so that she knew where to aim the aperture over her stoma [Fig 2].

"She would then hold the pouch in position, to warm up the backing plate and skin to get good adhesion." [Fig 3]

The above is taken from a poster presented at the Association of Stoma Care Nurses (ASCN) Conference. Sally



Fig 3

Wright is a Community Stoma Nurse Specialist for Amcare Group Nursing Service (a ConvaTec company).

Sharing Hints & Tips

I received an email from one of my support group members that I think is worth passing on.

She says: "I have a tip for odour control which works very well for me. Medicinal charcoal tablets, that are designed to be swallowed, work very well if just half of one is popped into the bag. At £3.00 for 100 tablets they are very economical too. I can certainly recommend them."

I know that a lot of ostomates are very worried about odour and this seems like a great and cheap idea.

Kind regards
Irene (CA volunteer)

I would like to thank Sheila who in the Summer edition of Tidings advised spraying baby oil into the pouch to reduce pancaking. Its use has made such a difference.

Ian

If you have an experience or anecdote you'd like to share, or hints and tips to pass on to other ostomates e-mail or write to the editorial team:

editor@colostomyassociation.org.uk

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Fare play to fund-raising cabbie



Taxi driver Steve Clark set out to raise funds and build awareness by donning a lurid wig for two busy shifts at the wheel of his cab. Here, his purple prose describes how it went:

When I read of **Colostomy Association** Awareness Day, I knew I wanted to do something. The question was what. The call was for volunteer ostomates to get involved in raising awareness of our community.

With the help of family and friends, a list of suggestions was drawn up and wearing an outrageous purple wig for 24 hours soon became the favourite idea. Now I'm known for being as daft as a brush, but still there was no getting away from the fact that donning a lurid purple headpiece for an entire day would not be without consequences.

I'm a taxi driver and on the day in question in October I was scheduled to be *duty car* for my company, Radio Taxis, on the Friday and Saturday night either side of the Awareness Day. Given the dubious character of some of my customers after chuck-out time, you may understand why later reflection made me doubtful about the exercise.

There is a joke and fancy dress shop in Fareham. It didn't have the kind of large and loud curly ensemble I was looking for (it would have been akin to turning the clock back 40 years as far as my hairstyle was concerned). Instead, I went for a long, straight wig and – though I say it myself – the result was quite becoming.

Once I had received the fund-raising pack from **Colostomy Association** Head Office, I set up a JustGiving account online, which included notes explaining the purpose of the account and details of the cause.

My wife, Cherry, took some photographs of me in the wig and a **Colostomy Association** polo shirt next to my taxi. We selected one and added it to the JustGiving page. The website included a field to set a target for donations. I plucked a figure out of the air – £1,000 – knowing I'd be happy even to raise £100.

All was set, but how was I to let people know what was afoot, both on the local taxi rank and further afield?

I started messaging all my Facebook friends, asking them to donate via the JustGiving link and to share the post on their own timelines. Members of the **Colostomy Association's** own closed Facebook group joined in enthusiastically and, before long, the pledges were starting to flow. My Twitter account was similarly useful. First, I added *Pls RT* (please re-tweet) to the end of the JustGiving link and then using the hash tags **#colostomy** and **#atabootofar** (thanks to Ian J for that suggestion).

I benefitted from plenty of re-tweets from followers on Twitter – 45,000 people over a two week period – but I still needed to get the message out to a still wider audience.

One who picked up the story on Twitter was a reporter for one of our local newspapers. She asked for pictures and interviewed me over the phone, the plan being for the piece to appear in the week leading up to Awareness Day. I had the Portsmouth News on board; now I would try the Southampton Echo.

I heard nothing until the third week of September, when a reporter from the Echo got in touch. The interview took an hour and the accompanying photographer took what seemed like hundreds of pictures of

me, both in normal working clothes and then in my **Colostomy Association**-purple-wig-polo-shirt outfit, again with the taxi.

That, in turn, provided what I hoped would be a further fund-raising opportunity. Would Radio Taxis be willing to make a donation in light of the press pictures showing the branded taxi? They said yes and approved a donation.

With seven days to go, I embarked on a major awareness campaign on Facebook and Twitter. Donations started flowing in, including a single pledge of £100. The fundraising was beginning to take on its own momentum and, by October 2, we passed £1,000. I was thrilled.

A BUNCH OF FIVES – OR A BUNCH OF FIVERS?

I started my shift at 9pm and couldn't help but wonder how people were going to react when they staggered out of the pub and into the car to be faced by...by a purple apparition. Was I going to get a bunch of fives or a bunch of fivers?

Thankfully, my first fare was a young woman. We had a lovely chat about why I was dressed as I was and a little about my own surgical history and she generously made a donation.

The next job was a fare from one local pub to another. Four guys, all somewhat merry. One of them – the chap seated in the front – offered me a look that said: what on earth is going on? "Hello honey," I said. "It's not all my own hair. It's a charity skit."

CONTINUED ON PAGE 18, COLUMN 1

UPDATES STEVE CLARK

CONTINUED FROM PAGE 17, COLUMN 3

The quip broke the ice and during the three-mile journey we had a great laugh while I tried to explain, in words of one syllable that would penetrate the alcoholic fog, what was afoot. They were really good fun and left a substantial donation in the box, alongside which was a **Colostomy Association** logo and a laminated sheet telling the story of the fund-raising campaign.

Friday night continued in a similar vein. Even one of my fellow taxi drivers donated and gave me a bonus of a big kiss and cuddle (she is rather gorgeous!). At 4:15am, I ended up on the rank, where another colleague took a final picture of me in my wig – still smiling. By the time I finished, I had just over £56 in the box.

Over lunch on the Saturday I got a bite to eat in the local, where I wore the weekend 'uniform'. I was immediately approached by

a woman who thrust five pounds into my hand. She knew all about me having seen a post of the local history group on Facebook. Others in the pub came over and put their odd coppers into the box and I left there with about £15.

At 3pm I grabbed a few hours' beauty sleep before another all-night stint on the road. Again, out at about 9pm, but this time the response wasn't as good. Although a few made donations, they weren't as frequent as the night before. A couple of local house parties seemed to include the game called 'mess the local taxi firms about' and I was not in a fund-raising frame of mind. In fact, I was rapidly losing my sense of humour.

Time to pull myself out of it. At 5am I had a run to Southampton airport with a lovely couple on their way to Alicante. They made a donation and also told me of their sister who used to be 'one of us' but had a

successful reversal. It was a heart-warming story, even for a 'lifer' like me. I arrived home, emptied the box and, amazingly, counted out nearly £52. It hadn't been such a bad night after all.

Overall, the total raised was a fantastic **£1,337.22**, in cash and online donations. Additions are still being made and, at the time of writing, the account is still open at: **www.justgiving.com/Steve-Clark13**

Donations can also be made by texting **CASC47 £5** to **70070**.

I would like to express my sincere thanks to everyone who helped with sharing posts, re-tweeting, donating and generally encouraging and inspiring me. I couldn't have done it without you. Thank you. Oh and the purple wig? Many have pointed out to me it was probably nearer pink!

Steve Clark



Page owner
Steve Clark

Steve's Colostomy Association Awareness Page

I wore near-purple wig(!) & CA polo shirt in taxi for Colostomy Association because it was fun with my customers in Fareham.



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Travel and the security inspection

With the various conflicts in the world and people from one country going off to fight alongside their brothers in another country and the constant fear of terrorism, the border security officers are under huge pressure to make sure they don't allow any fanatic through the security net and onto a ship, plane or train to wreak havoc with their plastic explosives.

As a result they have had to become ever more vigilant at trying to prevent terror attacks. Electronic Scanners are set to the highest level of sensitivity, random body searches are being intensified and occur more frequently. Soon they will want us to parade nude in front of them. Oh, actually they do that already by X-raying us at some of the airports. These potential threats mean security teams are under immense pressure to get it right.

What they want is for everyone to pass through the security inspection smoothly and without fuss. What they don't need is anyone who is different, unusual, or who makes a fuss, or who draws attention to themselves. We will all be wearing a colostomy pouch or a plug. It will show up on an X-ray but it won't set a metal detecting alarm off. Occasionally security officers will notice the bag when they do a body search but nine times out of ten times they either don't mention it when they have given us the once over with their hands or the magnetic wand. And if they do say anything, I tell them that I have a colostomy and that is it, "Thank you, Sir, on you go."

What I don't do is arrive at the security scanner in a great flurry and announce that I have a colostomy or that I can't go through because of my condition, or in any way draw attention to myself. We are all very

conscious of our colostomies but actually no one else really notices. If you sunbathed on the beach and your colostomy bag was showing, most people would take it for a bandage, a plaster. So I say nothing and generally no one notices. I make sure I have emptied or changed the pouch before arriving at the security scanner, of course. That's just sensible.

I will take everything with any metal in it off and put it in the tray. Glasses from my top pocket go in there, as does any pen, my belt, money in my trouser pockets, my watch. Most hearing aids will not set off the scanner alarms but I wouldn't chance it I'd put that in the tray too, if I had one. They will stop you putting it on there if they don't think it is necessary.

I am now standing there in my stockinged feet with nothing in my pockets, my

trousers sagging, no watch, no glasses, no pens about my person and I will sail through without a squeak.

If you have had a knee replacement or hip replacement or have any prosthetic limbs, or a pacemaker, you will need a letter from your doctor confirming that you have been fitted with this equipment. Have this in your hand as you go through the scanner. Don't mention anything unless the alarm goes off and then proffer the letter and explain why you think the alarm may have gone off. They will give you a quick body search just because they have to, to establish that it was the medical intervention rather than the fact that you have a Colt 45 tucked into the waistband of your trousers.

By the way taking guns through security is a **very, very bad idea**. Talking about guns

CONTINUED ON PAGE 20, COLUMN 1

Getting through security – without a hitch – Top Ten Rules

1. Do not draw attention to yourself.
2. Change/empty your bag before you enter the security check area.
3. Pay attention and do exactly what they ask. If they want laptops/ipads/tablets out of their cases, charged up and operating, then make sure that yours is charged up and taken out of the case.
4. Take your travel certificate with you.
5. Take any doctor's letter that you may need with you.
6. Accept that they may need to search your body. Do not resist and stay calm throughout.
7. Mention the colostomy and ask to be taken to a private room.
8. Make sure that all liquids are in a bottle of 100ml or less and in a plastic bag so they can be seen clearly.
9. If you need to take scissors then make sure they are round ended and less than 6cms in length.
10. Place everything about your person, that might set the scanner off, into the plastic tray – belts, tie pins, glasses, keys, loose change, metal hair clips, rings, earing rings, hearing aids (you will be told if this is not necessary).

LIVING WITH A STOMA AIRPORT SECURITY

CONTINUED FROM PAGE 19, COLUMN 3

or bombs in around or near the security area or the check in is a **very, very bad idea**. Making jokes: "And did you pack the bag yourself, Sir?"

"Certainly did, had terrible trouble getting the Bazooka in..." is a **very, very bad idea**. Security people take security very seriously and thank goodness they do. It is for our own welfare after all.

I read this piece of wickedness on an American website recently:

The body scanner picked up the bag of course so the USA security people asked me, "What's up?" I said: "I have a medical device". So they checked my hands for explosive residue. Of course I am very careful when I load my bag with TNT not to get any of it on my hands... ha ha...

When we talk about metal things, I would take off any rings if I wore any. I would also take my ear rings out and if I had body piercings this would be the one day that I would remove them, all of them. I want to go through that scanner without a squeak. Set it off by being careless and we bring down on our head what we deserve.

If you happen to be the random person that they need to do a more thorough body search on, you will just have to go along

with it. They may be nice, they may be curt, they may be officious. It doesn't matter you just do what they say, agree with everything and you will get through much quicker than if you answer back or comment. If they want to look at something out in the public area, you tell them quietly that you have a colostomy and ask if it is possible to go somewhere private. You show them your travel certificate.

If challenged in public and the security officer refuses to take you to a private room, I would discretely raise my shirt to reveal the appliance without making a fuss, in the hope that they might then decide to conduct the search in private.

Calmness, co-operation and politeness are key to ensuring your travel experience is not adversely affected. There will be some security officers who will almost certainly not know what a stoma bag is.

Some people ask about taking scissors in their hand luggage. Most colostomates will have their flanges pre-cut for them but there may be those who need to trim flange extenders and so forth. Round-ended, blunt scissors and knives less than 6cm are permitted in hand luggage. Hypodermic syringes for medical reasons are allowed – you will need a doctor's letter explaining why you need them. And of course liquids

and aerosols (air fresheners) in a bottle of 100ml or less are allowed.

So, the long and short of it is that as a colostomate one rarely gets noticed. I have never had any trouble. I have had the occasional search, the hands over the body but no more. Once when I was travelling with Sarah Squire up to Edinburgh for some volunteer training, she got stopped. She had a sacral nerve implant at the time and had gone through the scanner ahead of me and had set it off. She explained why she thought it might have gone off and the security man and woman asked her to go with them. I was waiting to go through the scanner. They asked Sarah if she would like me to come in with her. "Certainly not," she said. "He's not my husband." She was only in there for a second and they were very nice. We went off clucking away just like husband and wife, only not. Obviously.

So, we help ourselves by not drawing attention to ourselves.

Finally to guarantee that we will have our supplies with us when we get to the other end it is necessary to take everything in your hand luggage. If this will put you over the limits, then contact the airline beforehand and discuss it with them. They are usually more than happy to help and there are extra allowances for this sort of thing.

Duncan Wells

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Cruising with a colostomy



Library picture

I first took my colostomy on a cruise when “she” was quite new, barely six months old. It was, in fact, the first time that we had been away together, anywhere.

I would not normally recommend the Nile for a first cruise but this had been booked before my diagnosis and I did not want to let the rest of the family down by cancelling.

Nothing untoward happened on the four hour flight to Cairo or on the transfer to the hotel at the pyramids. Our first outing was to a Coptic church in old Cairo, the approach road went through a short tunnel which was full of material that had overflowed from the drains. “Nothing to do with me” I thought, as we carefully picked our way through – in sandals.

After two or three days we joined our Nile Cruiser. We had a vast bathroom where I found something on which to hook my reservoir and had no trouble irrigating. While waiting for the morning wash out to finish one could watch the fascinating river bank through our enormous cabin window. Irrigation was never so enjoyable!

We visited many tombs and noted that the Pharaohs never had drainage problems. Cruising up the Nile remains one of my most memorable recollections, sitting on deck in the sun, while a sort of biblical parade glides by, donkeys, buffalo, palm trees, children waving, men and women in flowing robes collecting water and tending their crops, and ramshackle houses.

We washed our hands before meals and avoided salads, water melon, ice and dodgy roadside drinks. Nevertheless the bug got us all in time. When I was struck with *Pharaoh’s revenge* I was confident that I could cope with a drainable pouch and sallied forth to see Tut-en-Kamun without

fear of accidents. At the end of the cruise someone congratulated me on seeing every temple and commented that I had done well to avoid the dreaded lurgie. Instead of expounding the advantages of having a stoma I’m afraid I smiled and went on my way.

Cruising is fine for colostomates, on board you are always within walking distance of your cabin and a well-equipped bathroom with shower. Even in the QE2 or some other floating hotel you are never far from a public loo, as there is usually one on every deck. It is worth locating these on your first day when finding your way around the ship.

We did a few cruises in what might be called yachts where cabins were small and it was often difficult to find safe places to put the bits and pieces required when changing a pouch. So I put everything I needed for one change in a pocket sized plastic bag which did not slide off the basin when the vessel rolled.

These ‘en suites’ were pretty cramped, everything took a shower with you so it was unwise to take in much more than a towel. One rough day, in a Turkish gulet my wife grabbed the basin for support when she was showering, to her surprise half of it came away and both ended on the floor.

It was terribly hot on that particular cruise so it was great to be able to jump overboard for a swim in the evening when we anchored. To make matters worse my colostomy was prolapsing and I had to lie on the floor to push it in before a pouch could be fitted, this meant that the new pouch often did not adhere properly and I was getting through my stock rather more quickly than planned. At that time, I believe, there was only one stoma nurse in Turkey and she was in Ankara about 250 miles

CONTINUED ON PAGE 22, COLUMN 1



In 2013 Robin Mills was awarded the Colostomy Association Volunteer Lifetime Achievement Award for his commitment to helping colostomates over the past 28 years.

Robin had his stoma operation in 1984 and soon after joined the Colostomy Welfare Group (CWG). Local stoma care nurses would call on him to visit patients after stoma surgery. The CWG became the British Colostomy Association (BCA) in 1989 and Robin was appointed Area Organiser for Hertfordshire and recruited Visitors in East Anglia. He attended the International Ostomy Association Conference in Adelaide while visiting friends in Australia. When the **Colostomy Association** was formed in 2005, Robin was one of the founding Trustees.

Over the years Robin has worked as a voluntary visitor in hospitals across several counties visiting countless pre and post op stoma patients and has built up a relationship of trust with stoma care nurses. He has attended hundreds of open days and took his turn at manning the Out of Hours Helpline for many years.

In August 2014, Robin was among British war veterans awarded the Ushakov medal for his service as a Midshipman in a cruiser escorting Arctic convoys. After the war he was minesweeping and surveying. His last job was managing the shipping of leaf tobacco. One of his hobbies was skiing which he gave up at the age of 84. His other hobby was cruising – 13 years in the Navy, including two voyages to Australia and back and nearly 40 cruises in European waters. To complete the circle a stoma care nurse recently thanked him for helping a patient he met on a Mediterranean cruise.

REAL LIVES ROBIN MILLS

CONTINUED FROM PAGE 21, COLUMN 2

away! I wondered if our excellent manufacturers could get more pouches to me in time, but I did not have their telephone number. Anyway you will be relieved to hear that I got home with one pouch in hand – a lesson learnt for the future.

If your cruise takes you to places where you are likely to encounter a hole in the floor, with or without foot pads, make sure that you are wearing a drainable pouch as it is usually impossible to change a closed one and clean up in such a toilet. I never recommend changing in a train, at all costs avoid the lower classes of coach on the Indian railways where the hole opens onto the track.

'Only put toilet paper in the W.C.' is an instruction that must be obeyed at sea. Failing to follow it has the most awful consequences. The plumbing system has to be shut down while men in overalls search for the offending blockage.

In one vessel the drains even went into reverse, overflowing into hand basins. Some small vessels go even further and require you to place all toilet paper in a bin. This applies on land too, in places like Greece and Turkey.

In the very old days when ships had an overhanging stern the loos were situated there because plumbing and flushing were not necessary, however in very rough weather you were liable to be 'pooped' if a wave hit the stem. In the last war, large

American warships naturally had large 'heads' and although there were partitions between cubicles, the 'drain' was a trough that ran through them all, in Roman fashion. Unlike the Romans who had stone seats, our allies sat on crude bars either side of the trough. Water from the fire main flowed along this trough and washed everything out into the sea. Occasionally it was used to float a sort of fire-ship of blazing paper under the unsuspecting sailors in the downstream cubicles.

Cruising is a fabulous thing to do and it really is very straight forward managing one's colostomy, even on vessels with the most rudimentary facilities.

Robin Mills



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peel open

The importance of Lasting Powers of Attorney



Rachel Fuller

Royce & Co, Solicitors

In my last article I looked at the importance of making a will. The importance of making a Lasting Power of Attorney ('LPA') should not be underestimated either as a means of easing the burden on your loved ones trying to manage your affairs on your behalf.

The Alzheimer's Society estimate that by 2025, more than a million people in the UK will have dementia. Without a LPA, handling your financial affairs would be virtually impossible as no institution, asset holder or third party will accept instructions without one if you have lost capacity. An application to the Office of the Public Guardian for the appointment of a Deputy would have to be made in order to get access and manage your assets and finances which can be a lengthy and expensive process. There are also ongoing requirements that a Deputy must fulfil such as paying an annual fee and also submitting an annual report. So it can be easier for someone to be an Attorney rather than a Deputy.

LPAs were introduced in October 2007 to replace Enduring Powers of Attorney ('EPA') although EPAs created before October 2007 remain valid. LPAs were introduced to reduce the potential abuse which is why they are lengthy documents with various checks and safeguards in place.

As with wills, there are various misconceptions that LPAs are only for the elderly and infirm. On the contrary, once you have lost your marbles, it is too late to make an LPA and so the Deputyship route would have to be adopted. So, it is better to act sooner rather than later to avoid the untold stress on your loved one trying to manage your affairs with no authority to do so.

Why should you make a LPA?

- If you are unable to make a decision for yourself in the future, your chosen person will be able to make these decisions for you.
- It ensures that the person you want to make decisions for you will be able to do so. This prevents a stranger, or someone you may not trust, from having this power.
- It can reduce problems that may occur in the future. It can be more expensive and time-consuming for family or friends

to try to gain a similar power in the form of a Deputyship Order in the future.

- It can help prompt discussions with your family or others about your future wishes.

What does a LPA allow your Attorneys to do?

There are two types of LPA:

1. A Property and Financial Affairs LPA gives your Attorney/s authority to make decisions about:

- collecting your income and benefits;
- how to spend your money;
- buying and selling your property;
- paying the mortgage;
- arranging repairs to your property;
- giving people access to your financial information;
- dealing with your bills;
- running your bank accounts and
- investing your money.

This LPA can be used by your Attorney/s, with your agreement, even if you still have mental capacity but perhaps have a physical disability. These powers can be restricted or conditions can be placed on them in the LPA.

2. A Health and Welfare LPA gives your Attorney/s authority to make decisions about:

- refusing or consenting to treatment (including life sustaining treatment);
- where you should live;
- what kind of social activities you can participate in;
- how you should be treated medically;
- your day to day care including your diet and what you wear; and
- who you should have contact with.

This LPA is used by your Attorney/s once you have lost mental capacity and can include specifics if you wish.

How do you make a LPA?

First of all, you need to select your Attorneys. They will make all decisions in your best interests and follow certain principles set out in the Mental Capacity

Act. They must be someone:

- you can trust;
- who is reliable and has the skills to carry out the role;
- who is not bankrupt; and
- who is willing to take on the role.

Secondly, you will need to select a Certificate Provider who will certify (a) that you still have your marbles and understand the nature and effect of LPA and (b) that you have not been forced into signing it. They must be someone:

- who is a professional and can certify that you have mental capacity based on their assessment of you and their experience in this area; or
- someone who has known you for more than two years.

Thirdly you will need to select a Named Person who receives a Notice that there is an application to register the LPA. This could be anyone you know and trust and this Named Person provides you with an additional safeguard. If none are listed, an additional Certificate Provider must be provided. The Named Person has an opportunity to write to the Office of the Public Guardian upon being given the Notice and advise them of any undue influence or potential abuse that they are concerned about when you signed the LPA.

Once all of the documentation has been signed, it is sent to the Office of the Public Guardian together with a cheque for £110 per LPA for registration that will take at least 4 weeks and has been known to take 12 weeks. Once registered, a fully certified copy can be sent to the institution, asset holder or third party who will then recognise the Attorney's authority to act on your behalf. The original can either be stored with your solicitor or with you.

Rachel Fuller

In our next issue, Rachel looks at *legacies*.

For more information visit:
www.gov.uk/power-of-attorney/overview



I am a counsellor with particular interest in relationship therapy and psychosexual therapy. I myself have had a stoma for nearly seven years and I met my husband five months after my first surgery.

Life before my stoma was pretty rough. I was doubly incontinent due to a third degree tear in childbirth, which caused irreparable damage to my bowel and bladder. I lived like this for eight years as my then husband didn't want me to have a stoma.

As soon as he left, I decided it was my body and my choice. I set the wheels in motion for the surgery. Although at times life with a stoma can be challenging, I was able to regain control of my body and my life. It was the best decision for me. My life was transformed for the better.

When asked to write an article on sex and the stoma, I was delighted, as so often these subjects are taboo and simply not discussed. People are squeamish, embarrassed or both. I want to try and break this taboo in order to boost the confidence of colostomates and their partners. Your stoma is part of you and, for many, there is no changing that. We have to get used to it.

Body confidence is so important for a healthy sexual relationship to flourish. To begin with, having a stoma can knock your confidence. I can remember standing in front of the mirror naked with this 'thing' hanging from my tummy. How could someone love me like this? Gok Wan wouldn't want me on his programme, *How to look good naked*, because I simply didn't think I did.

At the time of my surgery I was single and, if I'm honest, I didn't think I'd ever have another relationship, even though I was

only 34 years old. Sex was not on the cards for me and certainly not the dating scene. However, meeting a tall, dark and handsome man one day changed my thinking. Could it really be possible?

I couldn't stop talking about him with my friends, but lacked the courage to do anything about it. My friends pressurised me into inviting him to my birthday party, and he came! At the end of the evening he kissed me and wow what a kiss it was! I had never been kissed with such passion and tenderness. It truly was a *Mills and Boon* moment. Once I had learnt how to breathe again we planned to meet the next day.

The next evening he came over to see me. I was really worried how I would tell him at some point in the future that I had a stoma. Should I have said, before you kiss me I must tell you I have a stoma? No of course not. I wasn't even sure if there would be a relationship anyway as we'd only had one kiss, albeit a mind blowingly intense kiss. We sat on the couch talking to each other for a while and we started kissing again – then I realised his hand was sliding up my thigh. Panic set in and I launched myself off the couch like the NASA space shuttle on take off.

A look of bewilderment and surprise was on his face. He asked me what was wrong and I told him that I didn't want to tell him this yet, but I have a colostomy. I thought I'd blown it and he'd be out of the door at a similar speed to my exit from the couch. He looked at me, held my hand and said: "Well at least you don't have two heads!" He gave me a great big hug and I sunk into his reassuring arms and he told me we could take it as slow as I wanted.

Months later he admitted to me that at the time he had no idea what a colostomy was,

and had gone off to research it after that second meeting. This is an important point – when you do tell someone that you have a stoma, don't assume that they know what it is! It's a fine balance between telling too much gruesome detail, and not telling enough – either extreme can put people off for different reasons. My advice would be to suggest that they ring the **Colostomy Association** 24 hour Helpline where a member of staff or a volunteer will be able to explain the details. This will give your potential partner an opportunity to ask difficult questions that they don't want to ask you, such as what limitations and special provisions are needed when you're in a relationship with a colostomate. *Google* might scare them.

The knowledge that someone was interested in me despite having a stoma boosted my confidence. I can remember doing my housework the following day, dancing around to ABBA blaring out of the stereo. I knew that although I had many hurdles to overcome – the prospect, at some time in the future, of having sex now seemed a possibility.

So how do you make that first step towards a sexual relationship? Your body has changed and you can feel very fragile emotionally and physically. It can take a few months for your body to heal after surgery. You must take your time and only go further when you both feel ready. Take into consideration your partner's feelings as well as your own. The key to this is honesty and communication. Talk to each other about what you want and what you need. It doesn't have to be all or nothing. There is so much that you can do to be sexually intimate without penetrative sex. Sometimes in stoma surgery the nerves to the sex organs can be damaged or severed, resulting in difficulties with arousal and

libido. To deal with this you may need professional help.

Take time to discover one another's bodies with gentle caressing. Basically have fun experimenting with new ways to arouse and delight in each other's company. You are beautiful, even with a stoma and remember your partner is there because they want to be. Just remember to have a sense of humour and enjoy the experience.

You won't forget the stoma is there and neither will your partner but you can learn to adapt your thinking so that it is not your first thought. For me, the feeling of being caressed and cherished was enough to push the thoughts of the stoma to the back of my mind and let myself be absorbed by the intimacy and passion.

That doesn't mean to say that the thoughts stay that way. Stomas can have a funny knack of interrupting with the odd noise. That's why I say you need a sense of humour. It's no difference to your partner breaking wind during your intimate time. It's a natural function.

Be sexy, even if at first you don't feel sexy. One way for women to achieve this is to wear crotch-less knickers. There are companies out there, which do beautiful underwear, which is not only practical for ostomates but also sexy. I found that I could



get sexy pants with matching camisoles, slightly longer than the average garment you may buy on the high street, which means that the camisole can cover the stoma area on its own. Another way of shielding the stoma area during sexual intimacy is to wear a support band, which, when worn upside down, envelopes the pouch with total security.

I personally feel like an Egyptian bandaged mummy in this and so I have designed a lace band which not only covers the stoma area, it also holds the pouch in place with no worries about it slipping at the crucial moment. I was unable to find a product like this that was both affordable and sexy. My design cost pence to make but is priceless in how it makes me feel.

Sexual intimacy with a stoma can be successfully achieved with a little pre planning. I would advise ostomates to empty their bladder and change their bag before sexual intimacy, especially if you also

LIVING WITH A STOMA INTIMACY

suffer with weak pelvic floor muscles, bladder problems or heavy output from the stoma. Various kinds of stoma caps are available. They are neat and discrete, no bigger than the circumference of an average drinks tumbler, but there is still a small area inside which can hold any output should the need arise. I can remember my stoma nurse saying that they were for leisure and pleasure. I thought at that time: "Yeah right! Like I'm going to need that. Who'll have me now?" (Little did I know!)

My husband and I have recently celebrated our third wedding anniversary and, although from time living with a stoma can be challenging for both of us, we are honest about our feelings and never stop communicating.

Any marriage has to be worked at to be successful. Maybe we colostomates and partners need to work a little harder as living with a stoma is an ongoing challenge. There are no easy fixes for coping with this, however I believe that honesty and communication on both sides is key.

There is no reason why you can't have a successful and fulfilling sexual relationship with a stoma.

So take the first step and rediscover yourself. You never know, you might just like it!

Sarah Anderson



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Szewczyk MT, Majewska GM, Cabral MV, Hölzel-Piontek K. Osmose Study: Multinational Evaluation of the Peristomal Condition in Ostomates Using Moldable Skin Barriers. Poster presented at ECET, Paris, France, June 2013.

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So gentlemen, what Sarah has written may be fine for a lovely young lady in the prime of life, but what about us of more mature years.

Like Sarah I met someone after I had the operation. I lost my wife of thirty years in 2010 when I was a sprightly 63 year old. Who would want me?

Well my grey bearded charms lured a lady 15 years younger and I maintained her interest on our dates until we got to the point of intimacy. I had managed our dates without any huffing or puffing from my pouch, but there comes a time when you just have to tackle the point, before you get too emotionally involved. This was my first involvement with anyone for 33 years, so my romancing skills were still being re-honed.

I have to say that, what attracted us was our exceptional ability to communicate well

and be open with each other. So, in one of our "let's get it all out" discussions I started, "Well, Pauline, I have not mentioned it before as I am a little nervous and not sure how you might take it. I would like you to know now..."

Her response: "Thanks for telling me. What's the problem?" or something like that. I cannot remember her specific words because there was little discussion on the topic, and no negative issues arose.

Not being a trained psychosexual therapist I do not have the eloquence that Sarah portrayed in her writing. Besides, there is no point in repeating what she has already covered. Body confidence matters to us males as well, and being a naturist, I had already dealt with strolling around naked at holiday resorts and camping as well as the occasional opportunity on my boat. So I had no issues looking in the mirror. However, I

did have concerns about arousal.

Now I have to be honest, and there is no getting away from it gents, women are much better than us in general. To women, a relationship is not so much a physical thing, as us guys see it. However, I still had the problem of performance. I warned her that there was a chance my clanger might not ring the bell again, so I needed some help. Well she was great.

Have to admit that the bag did not exactly support my manly image when I looked in the mirror on this occasion, and wondered what impact it might have on Pauline; so I tried a plug.

Having been to the doctor to discuss my concerns soon after my operation, he prescribed Viagra but due to my wife's illness, other things took greater priority and I had never tried them.

CONTINUED ON PAGE 28, COLUMN 1



LIVING WITH A STOMA INTIMACY

CONTINUED FROM PAGE 27, COLUMN 3

So, I donned a plug rather than a bag, swallowed a Viagra pill and tally ho.

The first time was not perfect but I felt a man again and relieved that our romance might have a chance of developing and being normal. As time went by my confidence grew and after one romantic episode Pauline stuck a Gold Star on my forehead (literally).

When we moved in together, our sexual activities became more spontaneous and I never had a chance to slip a plug in or swallow a pill but we still enjoyed ourselves. I now find the Viagra is more of a placebo than a necessity.

We both enjoy sex and I began to appreciate that sex does not have to be the ultimate act every time and that variety is the spice of life. I sometimes find the CUI Wear Girdle I bought, to support me when I go sailing, can also help.

It hides your pouch, saves having to put a cap on and feels quite manly.



Mens Girdle No Legs – used by kind permission of CUI

So, if you are having problems, the lessons I have learned are:

- Talk to your partner and let them know your feelings and concerns.
- Consult with your doctor and check if it's psychological or physical.
- Use what "props" you can to get your sex life started again.
- Let "Great Expectations" be something to aim for at some future point and just take pleasure in what enjoyment you get.
- Practice makes perfect and if it doesn't, you will have a great time trying.

And here are a few clichés that might help.

Smile and the world smiles with; cry and you cry alone.

If you don't try you will never know.

If you think you can, you can. If you think you can't, you can't.



Vitala plug – used by kind permission of ConvaTec

Finally, I have recently discovered the ConvaTec Vitala plug which overcomes many of the potential side effects of sex and a plug (steam letting and leakage). I investigated using them permanently but they are expensive and I don't expect my GP will allow it. However, I might buy some for the special occasions like the celebration of our first Wedding Anniversary.

Trevor Andrews



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Irrigation and you

Sarah Squire, Trustee writes: With Christmas and New Year festivities over, many of us will be starting to think about holidays. As colostomates, we need to think carefully about the supplies we will need while away. Brian Kirkby is a keen cyclist and explains why being an irrigator is an advantage when it comes to packing for a cycle tour.

Before embarking on an adventure of this nature it is essential to build up one's stamina to the point where it is easy to cycle 30 to 40 miles per day, every day.

I am convinced that cycling aided my recovery from bowel cancer and a colostomy: thirty sessions of chemo through 2006, recovery in 2007 and then the start of my cycle adventures in 2008. It also coincided with managing my colostomy by irrigation which was an uplifting experience. Putting the two together has given me a new lease of life which at 77 is wonderful.

Cycle touring with a colostomy is not governed by distance but by how many bags, caps or sleeves can be carried on the bike. I use four panniers, two on the front forks and two on the rear carrier plus the option of a small sack across the top of the rear carrier. If I manage the colostomy using a two-piece system I would, on average, use 3 bags per day and a base plate every 3 days. For a tour of 21 days this would equate to 63 bags and 7 base plates plus wipes, sprays, and disposal bags and would fill one pannier. Now comes the dilemma, two panniers for all the colostomy products and potentially go twice the distance? Reduce the clothes to a minimum knowing that as the tour progresses the colostomy products would reduce and space develop?

However, I manage my colostomy by irrigation which presents an entirely different option which is focussed on distance rather than pannier capacity. For example, I have recently returned from a round tour from Rutland in the UK to Vienna. I was away for 70 days, required 35 caps and drain sleeves which together with the irrigation kit occupied one pannier. Forty to fifty miles per day is easily achieved by either method of management but irrigation has the greater range, hence a round trip of 3,000 miles was possible.

Irrigation has potentially one problem, a place to hang the water bag, but as previous articles in *Tidings* have shown this is more imagined than real, most bathrooms position the toilet close to a door or shower cubicle on which to hang it. On the recent trip I used my telescopic bag support only three times but it was

essential that I had such a device as there was nowhere to hang the bag.

In The Netherlands and Germany accommodation is far more plentiful than in the UK with B&Bs, guest houses or small hotels along the popular cycle routes so it was only necessary to pre book a B&B in Lincoln on the way to the ferry at Hull, and a B&B for the first night in The Netherlands. After that I could find a place using the GPS on the bike, local tourist offices or the Bed + Bike scheme which operates in Germany. Cash only was also something to be prepared for as many of the small establishments don't take credit cards especially Visa due to the high fees. Who can blame them when they are charging only €35 or €40 for bed and breakfast.

For me time is not an issue as I am retired so a circular tour is quite easy to cope with. However, for those who have a limited time or who don't fancy the distance the trains in Europe will take bikes far more readily than in the UK. Alternatively the Bike Express Bus offers a weekly service to France and Spain for the option of cycling one way.

Though I didn't start cycling until 2008, I have tried several bikes. The first was a roadster type that was too heavy, then a folding bike, followed by a hybrid which was close to what I really needed. A tour

bicycle came next – a British designed bike ideal for touring – and it covered over 10,000 miles. Finally an electric bike. As I mentioned I'm 77 and the hills in Rutland seem to be getting steeper and this could be the way to keep cycling for a few more years. It certainly proved its capability on this last trip to Vienna.

What next? I'm toying with the idea of the ferry from Portsmouth to Bilbao, then to Avignon in France via Millau to see the bridge in the clouds and back along the Rhone and Rhine to Rotterdam and home.

Brian Kirby

Some great tips there from Brian which will hopefully inspire a few people to hop on their bike! Brian mentioned he uses a telescopic pole when there is nowhere to hang his water reservoir. You may also find a suction hook is a handy thing to pack, to stick to wall tiles, although Brian warns that some are very strong so take care when removing it not to take the tile off too! Reusable hooks such as those made by Command are also very good to and are very strong and stick to most smooth surfaces. If anyone has any tips for the travelling irrigator please write in and let me know and perhaps we can look at a "hints and tips" article next time.

Happy irrigating!



The picture demonstrates the difference between the colostomy management systems for a cycle tour of 50 days. On the left the supplies needed for the traditional management of my colostomy and on the right the supplies needed for the trip as an irrigator.

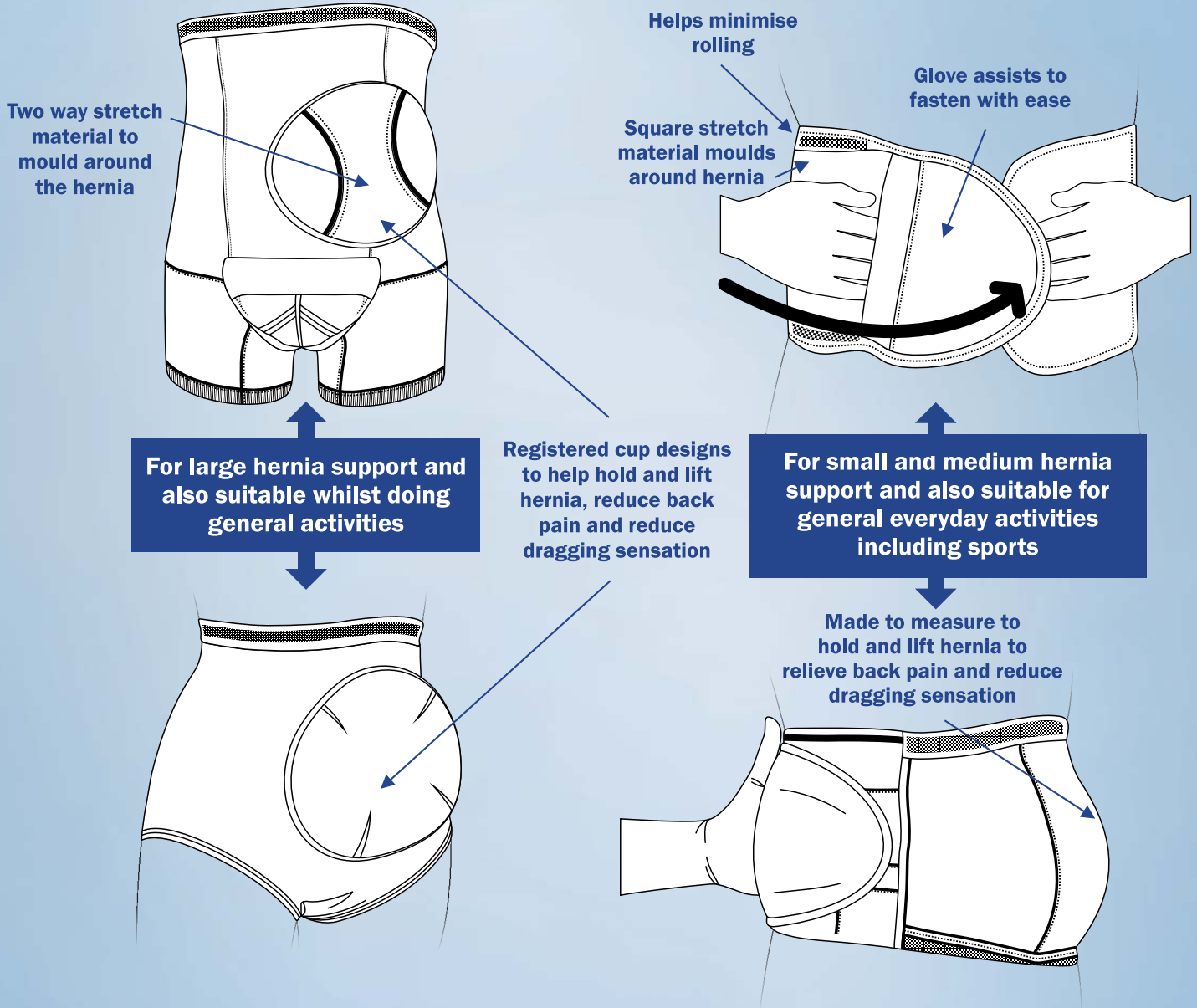
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Still Here...

..Forty years later



This year I am marking my 40th anniversary. In 1974 I thought I was done for but I am still here thanks to life saving surgery and a colostomy.

It's something to celebrate, not to be embarrassed about, because I have had 40 years of life when I might otherwise have died. I don't consider myself to be any kind of freak, I'm just glad to be alive. I don't hide from the fact and if I can help anyone else by talking about it I will.

It all began when I was on holiday with my wife, Maureen, and seven year old daughter, Tracy. I was 38 years old and feeling on top of the world. Because I didn't feel ill, I wasn't overly worried when I went to the toilet and noticed a little bit of blood. I ignored it but as the week went on there was more and more. When I got back home I thought I'd better go to the doctor and get it sorted out.

I didn't think anything serious was wrong, but the doctor must have been concerned because he arranged straight away for me to see a specialist. At the hospital they did some tests and then the following Wednesday the specialist called me back and broke the awful news. I had bowel cancer.

How could I go from feeling almost fine to being seriously ill? I had been in the process of painting the outside of my house. Suddenly I had to go into hospital. My job as a postman would have to go on hold for some time.

Two days later I was admitted to hospital. The operation took six hours. For my loved ones it was a very traumatic time as nobody

knew if I would survive or not. But I was completely out of it and was not brought round until Wednesday.

Gradually I came to understand what had happened to me. I had never heard of a colostomy and had no idea of what it was. The stoma was a bit like a strawberry with an opening in it. Things have come a long way since then and stoma appliances are much, much better now.

In 1974 mine was held in place by a buckled belt about an inch wide and made of canvas, rather like webbing. If I moved too quickly the belt would move, and occasionally even made the stoma bleed. It was very awkward and worrying. I got some leaflets which said that stomas had been around since 1700 and I was quite pleased about that. It meant I wasn't the only one by a very long way. I was told I would be in hospital for quite some time. Nowadays they get people out much more quickly.

I was in for 11 weeks. After two or three weeks I was able to get out of bed, hauling my drip with me on a wheeled stand. In the middle of the night I might totter round to the nurses' station so I could have a chat because I was bored stiff. My weight went down to eight stone and I had to be built up again. For a man who had always been fit and very active it was a bit of a comedown but gradually my strength returned.

Having been cut down the front as well as stitched up behind, they had to give me saltbaths to encourage healing and prevent infection. Then one morning I must have got out of bed a little too quickly as my stitches down the front burst open. After

cleaning me up and repairing the stitches they put me back to bed with orders to stay put for a while. It was a low moment; I asked myself if this was what the rest of my life was going to be like. But things settled down. I started my salt baths again and the colostomy was still working well.

By now I had been in hospital since August and my wedding anniversary on October 11th was approaching. I didn't want to celebrate it in the infirmary. My surgeon agreed that I could go home with the warning that I mustn't go out of the house and if anything went wrong I must come straight back in.

My world expanded slightly from the confines of my little hospital room to our long lounge. Life was very difficult for the first few weeks. The bathroom was upstairs and it was only with great patience and strength that Maureen managed to get me up there each day for my salt bath. The only toilet was also at the top of what seemed like a mountain of steps, so I made do with a *gozunder* – a pot that goes under the bed.

At first I was embarrassed at the thought of Maureen seeing the dramatic changes which had been made to my body, but married couples can't hide things from each other for ever. I never asked her if she wanted to see it but, as she was bringing me a fresh pouch, naturally she did. There really isn't that much to see anyway. She didn't care what I looked like and said she was just happy I was still here.

It was wonderful when we finally plucked up the courage to begin making love again

CONTINUED ON PAGE 33, COLUMN 1

Update on stoma care products and services

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

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For further information or to request free samples of the **OstoFIX40 HydroAV** product please call **Freephone 0800 220 300**, email **enquiries@ostomart.co.uk** or visit our website **www.ostomart.co.uk**



HiLINE EZ-Wrap Unisex Hernia Support Belt with Aloe Vera coating

is designed to provide Medium to Firm Level hernia support or prophylactic support. The belts have many features including anti-roll grip effect waistband, reinforced support around hernia, flexible yet supportive material and the addition of a zip pocket for ease of application. The new **HiLINE EZ-Wrap** belt range is available



Confidence Natural – NEW soft cover!

Salts Healthcare are pleased to announce that they have introduced an improved soft cover on their most popular one-piece colostomy product range – **Confidence Natural**.

Along with its unique five-sided Flexifit® wafer infused with Aloe Vera extracts, which provides the perfect fit and can help to sooth the skin, the product now has the perfect feel! The new super-soft pouch cover material is:

- Gentler and more comfortable on your skin
- More water repellent and even quicker drying
- More durable
- Lighter in colour which provides more discretion under clothing

If you would like to try a sample please call **Freephone 0800 0282144** (England & Wales) or

0800 626388 (Scotland). Alternatively, email **samples@salts.co.uk**



CONTINUED FROM PAGE 31, COLUMN 3

and that, like everything else, was a question of trial and error, experimenting in positions which were comfortable to us both. That is all very private, but I would like to assure anyone with the same health problem as me that all was very satisfactory, once we'd had a bit of practice.

My employers at the Post Office were very supportive. Two union representatives had come to see me in hospital with the reassurance that when I was well enough to work I would still have a job. If I couldn't manage a round they would create a job that I could do. For a married man with a young child, that was one worry off my mind.

By July I felt ready to return to work. We worked in groups of three taking turns at different tasks. My workmates told me they would do the other rounds further afield, leaving me to sort my mail then deliver to shops in the town centre near the sorting office, using the trolley. Three or four months later I told them I'd like to try driving the van. I couldn't lift anything heavy so my workmates loaded the parcels on board – didn't want to jeopardise all the good work that had been done by the hospital.

After two years I felt completely back to normal. Despite this I had to be realistic. The cancer could return and I didn't know

how long I would last. It didn't come back but I wasn't to know that.

My main concern was my wife and daughter. What would happen if I was no longer around to provide for them? With this in mind, we agreed to sell our large semi-detached home and move to a small terraced house nearer the town centre, paying off our mortgage. I told myself that if I didn't survive at least Maureen and Tracy would have a roof over their heads. For all my gloomy practicality, this house was to be our home for the next 28 years until we moved to a small retirement flat.

My courage building, I decided to take the family on holiday to Spain in the summer of 1976. We had a great time. My colostomy bag and belt sat discreetly beneath my swimming trunks but I couldn't risk going for a swim.

Today equipment is so much improved that it wouldn't be a problem and I have a friend who goes every week. However, I did take an unplanned dip. Tracy was playing in the shallow pool and began climbing on the bollards which separated it from the big pool. Suddenly she went splash into the deep water and, following any Dad's instinct, I leapt in after her.

The following day I got talking to a woman who had seen me jump into the pool after

Tracy. I told her how worried I'd been about the effect on my colostomy. To my surprise she said her mother had just had the same operation. She asked me to get in touch after we arrived back home and go over for a meal and talk to her mother about it. I did and the daughter was very grateful as she felt that her mother would now learn to live with it.

What a relief it was to throw that belt in the bin and change to a more modern appliance; one made of plastic – though the part that sticks on to the body feels to me like marzipan. The seals today are brilliant. Bending over is much easier. However, nothing is perfect and leaks happen now and again, but that's between me and my colostomy. Nobody else notices.

I'd like to wish other people with a colostomy all the best and encourage them to talk frankly about their stoma when they want to. I don't feel the need to tell everyone I meet, but I'm not embarrassed to talk about it.

People will still need colostomies but medicine is improving all the time enabling them to live long and normal lives, just as I have. The crucial word is **LIVING** with a colostomy.

We're still here!

Brian Kent

Update on stoma care products and services



Suportx are pleased to offer the Corsinel range of support products.

We provide a prompt delivery service and a free fitting service for the Corsinel range as well as our current Suportx ranges.

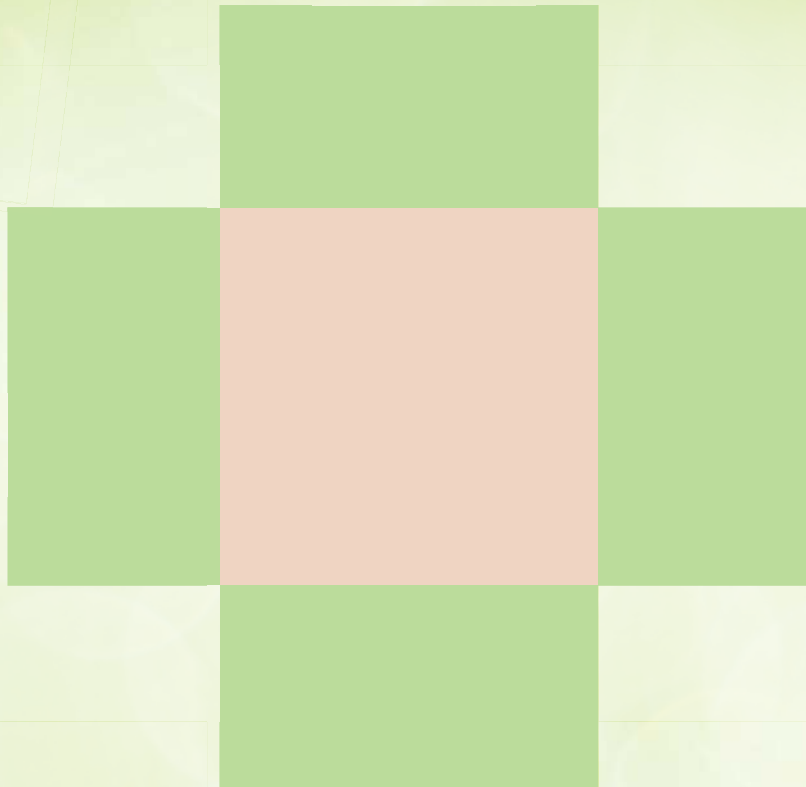
The Corsinel range now includes the **NEW** Stomasafe tube belt.

The Stomasafe belt is designed to support the stoma pouch. It is ideal to wear at night time as it assists in fixation of the stoma pouch.

It is also ideal to wear as a post-operative light support garment as it assists to keep the stoma bag secured and offers maximum discretion.

Stomasafe is available to buy directly from Suportx. For further information please see our advert on **page 14**, call **free 0800 9179584** or visit **www.stomasafe.co.uk**

NEW
SOFTER COVER



Now we've added even
more reasons to feel good about

Confidence® *Natural*

Confidence® Natural, with its unique, five-sided Flexifit® wafer, has always offered the perfect fit, whatever the size, the shape, or the type of your stoma. **Now we've added another plus – the perfect *feel* – too.**



Our new, super-soft pouch material is:

- + Gentler and more comfortable on your skin
- + More water repellent and even quicker drying
- + More durable
- + Lighter in colour, more subtle under clothing

Our research among patients showed:*

- + 90% considered it softer than their current cover
- + 97% felt the pouch dried very, or fairly, quickly
- + 100% thought it showed very, or fairly, good durability

**FOR FREE SAMPLES OR MORE INFORMATION CALL
FREEPHONE 0800 0282144 (ENGLAND & WALES) OR 0800 626388 (SCOTLAND)
ALTERNATIVELY, EMAIL [SAMPLES@SALTS.CO.UK](mailto:samples@salts.co.uk)**

Confidence®
Natural



Recognising Salts research
into healthy stoma skin



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SALTS
HEALTHCARE
www.salts.co.uk

*Salts data on file, 2014.

Total Diversion of life's pathway

**No, sorry,
it cannot be reversed...**

..there was no other way



CA volunteer, Farideh, shares her journey through a rollercoaster of events which have diverted her from the ordinary, normal life that she used to have.

It was seven years ago when I first saw my GP in Norfolk and complained of rectal bleeding and an itchy rectum. I was referred privately to a consultant at Sandringham Hospital. After seeing the consultant, I was given an injection into my sigmoid colon to stop the bleeding, which did stop. However, I was still feeling tired, lousy and lethargic – no one suggested a colonoscopy! I carried on as usual as if nothing was the matter with the usual quote: "I'm fine thank you."

Two years to that date I was diagnosed with bowel cancer. From there on I felt I did not have a chance to think. I was put through all sorts of investigatory procedures, saw different practitioners, nurses and consultants and ended up with an ileostomy pouch.

Managing my stoma was a difficult experience but I had to get on with it as no one else was going to do it. All the stoma care nurses were extremely helpful and sympathetic and they carried me till I was able to manage it myself. There was the constant hope of getting it reversed but in the meantime they thought I had a polyp and said it could be removed by Transanal Endoscopic Micro-Surgery (TEMS), a minimally invasive surgical technique. The operation was successful according to experts and I became even more hopeful of having the stoma reversed.

A year went by and I had a colonoscopy in 2011 when they said: "No, sorry, it cannot be reversed and you must start thinking of

having an end colostomy." How I felt is indescribable. I started arguing and wanting to find a way to avoid this but they all said there was no other way. So a date was booked for me to go and have a colostomy, but I still could not accept it and was very dissatisfied. When my consultant came to tell me about the operation and get the consent form signed I must have looked as if I wouldn't be able to go through with it, so at the last minute he decided to send me to St Mark's hospital in London for a second opinion. The diagnosis was the same so then I knew I had to have a permanent colostomy.

My whole life changed – I had to divert from the road I was on and start thinking how to manage with a 'different' me. What I could do and what I could not, what to eat and what not to eat, what sport and fitness program, travel, visiting friends and weekend stays etc. Then there were cultural issues. The list had no end. The thought is always in the back of your mind 'what if I have an accident where I should not have one?'

By profession I am an osteopath; I was running my own multi-disciplinary practice and was very focused on what I was doing and what I wanted. This mountain I faced was making me divert from all I had always worked for and loved to do. I did not want to let go easily.

Then I changed the way I was thinking and realised 'we are what we think'. It was time to make some serious decisions so I made a lot of changes in my daily life and sorted out some short term and long term goals. Most fell into place gradually with a bit of

patience while work had to be put on the back burner. One needs to be fit in my sort of job.

One of the first things which gave me hope and control over my daily life was irrigation. I started on that and am very happy with it. It gives me the control I need to go about my life.

I introduced a fitness programme into my life and started going back to Pilates and swimming. This gave me a feeling of being alive and able. Gently, I eased myself into volunteering with the **Colostomy Association** last year and back to work so my life was getting busy again.

Recently I was invited to present my story in the Post-Graduate Centre of Kent & Canterbury Hospital for the Stoma Master Class Study Day. I didn't have time to think about my own stoma and even forgot to take a spare pouch!

Now I do all that interests me. I volunteer for two other organisations: the Dover Detention Centre and Freedom from Torture. My role is to interpret when a detainee is claiming to have been tortured in their own country and is in fear of persecution so is seeking asylum. I also interpret for the detainee who cannot speak English when they are examined by a doctor and he writes his medical report. The doctor's report then goes to the Home Office and they decide the detainee's fate.

I go about my daily life exactly as it was before my operation – only I do more now and am involved in more diverse activities – and I'm loving it. It is worth remembering nothing is impossible, 'possible' is in the word itself.

Farideh

Association of St

Working Together to Provide Patient Support

Colostomy Association (CA), IA (the ileostomy and internal pouch Support Group), and Urostomy Association (UA) are all uniquely placed to provide quality support for patients who have had, or are about to have, life changing stoma surgery for colostomy, ileostomy, internal pouch, urostomy and other types of urinary diversion. The individual charities recognise they are best placed to assist ostomates in their own field and always refer enquiries to the appropriate organisation to ensure they receive the specialist support they need.

This support network for stoma patients in the UK and Ireland gives healthcare professionals a unique opportunity to promote an all-embracing quality service to their patients. Each charity has a wealth of personal experience, certified literature and a network of roll-overers or member organisations in this area of healthcare. All three organisations meet regularly with key health policy staff within manufacturing companies to help keep abreast of the latest NHS developments. In a united approach they also exhibit together at key national events such as Commissioning and Best Practice.

Additional Partners
Each quarter, representatives attend the Patients Industry Professionals Forum (PIPs) meeting in London facilitated by the British Healthcare Trades Association (BHITA). PIPs is a partnership between patients groups, industry and professional organisations, which officially launched in 2001 to address issues and challenges for patients, their families and carers, as well as to professionals in this area of healthcare. All three organisations meet regularly with key health policy staff within manufacturing companies to help keep abreast of the latest NHS developments. In a united approach they also exhibit together at key national events such as Commissioning and Best Practice.

Joint Campaigns
With the help of PIPs, in-charge leaflets are being despatched by Dispensing Appliances Contractors to ostomates whom the three charities simply would not otherwise reach. Campaigns against the issue of pesticide lottery prescribing and the restriction of patient choice are also taking place. Some Clinical Commissioning Groups (CCGs) are trying to reduce the quantity and choice of stoma supplies, and, in a joint approach, letters have been sent outlining the unintended consequences of such actions. It is hoped the Secretary of State for Health and Members of Parliament will become involved in this debate to ensure freedom of choice for patients.

We plan to continue our joint campaigns for the rights of ostomates as we are stronger together.

In autumn each year The Association of Stoma Care Nurses (ASCN) hold their annual conference over three days.

The **Colostomy Association** are invited to attend the event along with our sister charities, the Ileostomy Association (IA) and the Urostomy Association (UA) plus The Breakaway Foundation. It is a fantastic opportunity to touch base with many of the stoma nurses around the country and build on relationships with them, the other charities and the stoma care companies.

This year the conference was held at The Harrogate International Centre and the **Colostomy Association** was represented by myself, Duncan Wells (pictured on the right) and Sue Hale.

Rosemary Brierley, volunteer, former Trustee and Chair of the *Tidings* Editorial team joined us for the second and third day and Volunteers Jane Jones and Vanessa Denvir, each attended for one day.

The conference began with a reception on the evening of Tuesday 30th September so, after a frantic afternoon chasing missing packages which had been left in Birmingham by the courier, we were all set and the **Colostomy Association** table looked great.

This session is really an opportunity to welcome everyone to the conference over a drink and a chance to catch up with colleagues but already we were busy with stoma nurses visiting our table. After the reception we went out to dinner with the IA and UA and took the opportunity to have an informal tri-charity meeting to discuss how the three organisations can work together to be the bigger voice of the ostomate.

The next two days were rewarding but very tiring! The irrigation DVD proved a big hit and we were

giving a copy of the nurse DVD to anyone who hadn't yet received one. We completely ran out of DVDs so took orders to send out more once they are ready. We also got lots of positive feedback about it, many nurses saying it helped them and their patients gain in confidence about trying irrigation. It is so lovely to hear that the nurses like our literature and recommend it to their patients, many of

Support through You are

colostomy association

The CA Facebook Group is a closed group for colostomates and their carers. Importantly, membership is safe in the knowledge that only other group members can see discussions. Membership now stands at over 1000 members.

The CA Facebook group is an oasis for the first timer – "When people find the CA Facebook Group is wonderful to be part of you are in the world there will be someone on Facebook to help you."

Administration
The Group is run and moderated by four volunteers who devote much of their free time to making sure the group runs smoothly. You won't please all the people all the time, of course, people's tastes vary enormously. Their sensitivities vary. Many of the members will be fragile.

They often have issues with their colostomy. There will be those who won't leave the house because of it. There will be those who want to show and prove that their lives have not been blighted by it.

Many have issues with it. Many have yet to find that middle ground where they can live comfortably and normally with their colostomy.

Being part of the group they know they are not alone.

Example of Support
When I joined this group, it's fair to say I was in the deepest, darkest place ever... I joined this group and I don't post often, it saved my life.

Little boy in hospital at weekend, no support available and desperate parents.
Early one Sunday morning the Admin team received a message from a desperate mother who had been born with bowel problems and lung difficulties was very ill in hospital. He had been given a colostomy. The mother was very liquid output and the deal, he was suffering from it.

No one at the hospital was able to help for more than 24 hours. The little boy was in pain. How do you help?

The mother was surrounded by family and how bad was the situation?

We allowed the mother to have over a dozen chamomile lozenges.

The mother took the lozenges and posted that they were working. Hours, that the mother was now managing.

They found the solution.

To join the group and soon

Tel: 0118 959 1555

Since 2010, OstomyAid has been sending thousands of unwanted surplus stoma supplies to developing countries.

This project was initiated by Ostomy Lifestyle as they had identified the horror of people in certain countries having to use items such as plastic bags, nappies or tin cans to collect their waste following stoma surgery.

OstomyAid facilitated the redistribution of unused stoma supplies donated by individuals, support groups, stoma care nurses, charities and companies.

Improved pouches and hernia belt
Attempts by volunteers, insufficient funds have been raised to pay for a manager or to be able to afford new premises.

The Trustees of Ostomy Lifestyle and the Colostomy Association are working together to devise a way forward through a robust business plan to present to manufacturers and other businesses. We want to ensure that OstomyAid will be re-launched and will continue to support people whose lives are adversely affected by lack of stoma products.

We know that members of ASCN are supportive of this initiative and the significance of this project to emphasise the significance of this project to surplus supplies and promoting this project to patients and colleagues. Funds are desperately needed to continue this work and it is hoped this can be achieved by promotional work at clinics, open days and at support group meetings.

For more information please contact: **Angie Jeffries on 0118 234 0069**

To donate unused surplus stoma products, make a financial donation or to find out more about volunteering, please contact: **OstomyAid on 0118 234 0069** or visit ostomyaidostomylifestyle.org or telephone: **0118 234 0069**.

oma Care Nurses

them asking if we had anything new, or commenting on what they liked most. We met with stoma nurses new and old and at times all of us on the stand were busy trying to write down contact details, order DVDs and literature or answer questions! It was very productive in terms of *Tidings* too. Rosemary spoke to various people and got some very good ideas for future editions so watch this space!

We managed to attend a number of the presentations which were very interesting and informative. Lots of case studies are presented at ASCN along with a large number of posters which help us at the **Colostomy Association** understand what is happening in the stoma world and enable us to keep up to date and tailor our support appropriately. This year **Colostomy Association** were very fortunate to be able to present posters about our Facebook group, the 2015 10th Anniversary celebrations and a Tri-Charity poster along with IA and UA. They looked great and we hope to submit more next year.

At the end of the second day there is a gala dinner, an opportunity to relax a little after a long day on your feet. We sat on a table with Hazel Pixley and Brian Fretwell of UA, Julie Bastin and Sue Blackwell from Breakaway and Anne Demick and Stuart Hay from IA.

Many of you will have heard of Blake Beckford, the young ileostomate who has featured recently in the press after transforming his body post op to compete in body building events. He attended the conference as a guest of IA and also joined us for dinner. He is a lovely chap who is doing a great deal of good for awareness of life with a stoma and it was great to meet him.

During the three days at ASCN we got sore throats from talking and aching feet from standing but more importantly we represented you, the colostomate, in the stoma world and reinforced links with other parties to be able to continue to succeed and grow and support those who need us.

Support through Facebook You are not alone

The CA Facebook Group is a closed group ensuring a safe haven for colostomates and their carers. Importantly, members can post on the group safe in the knowledge that only other group members can see the discussions. Membership now stands at over 2,500!

The CA Facebook group is an oasis for the first timer - "You are not alone". The sense of relief when people from the CA Facebook Group is wonderful to see. Any time, day or night wherever you are in the world there will be someone on Facebook to respond to a post.

Administrators recruited by four volunteers who spend much of their free time to make sure the group runs smoothly. You won't be bored as there are always people all the time. Very many of the members will be happy to help. Their experience of life with a stoma will be helpful. Their sensitive nature who will listen and offer advice. There will be those who wish to share their own experiences. Many have shared with it. Many have yet to find that made a difference. When I joined this group, it felt like I was in the company of people who understood what I was going through. I don't post often, I started my life.

Example of Support

Little boy in hospital at weekend, no stoma nurse available and desperate parents. Early one Saturday morning the Admins of the group received a message from a desperate mum. Her 11 month old son who had colitis was in hospital. He had been given a colostomy at birth and because of his condition he was being treated with antibiotics and steroids. The mother wanted to point a picture of the stoma and his condition to the group and within a few minutes there were suggestions, from the advice of an 'egg' to the mother to look after the child and to get a bag on for the boy. The boy's stoma was recovering and that day the mother was able to take her son home. They loved that they were not alone.

No words to describe how much this group has helped me, to know you aren't the only one and there is always someone to help others - what more can I ask!

The group has a set of guidelines which are designed to protect the most vulnerable members. The subject of stoma photos was much discussed. Whilst it may be the first time a supportive reply may be given, it is a support query. Admins will allow it to be posted if it must be remembered as a course, the CA Facebook group can offer medical advice, just support and real life advice. It has been one of my stoma books. This group made me want to reach out to my area & connect everyone who struggles and I never want anyone to feel they are alone.

What tips? The Great has had a number of meet ups lately sponsored by the Colostomy Association. It may be the first time the colostomate has met someone who has the same experience and opportunity to help. The Great has had a number of meet ups lately sponsored by the Colostomy Association. It may be the first time the colostomate has met someone who has the same experience and opportunity to help. The Great has had a number of meet ups lately sponsored by the Colostomy Association. It may be the first time the colostomate has met someone who has the same experience and opportunity to help.

To join the group, search "Colostomy Association" on Facebook, choose the group and click the "Join" tab. One of the Admins will add you to the group as soon as they spot you waiting. We look forward to seeing you there.

Find us on Facebook

0118 939 1537 Email: info@colostomyassociation.org.uk Website: www.colostomyassociation.org.uk

Open Day 2015 & Fashion Show 2015: Celebration of our 10th Anniversary

Next year the Colostomy Association (CA) will be celebrating its 10th anniversary. Plans include an open day on **Saturday 11 July 2015**, a fundraising Gala Dinner that evening and a fashion show on the morning of **Sunday 12 July 2015**. Hope you can join us!

In 1963 the Colostomy Welfare Group was formed, going on to become the British Colostomy Association, until in 2005 the current organisation, the CA was established.

CA is a UK registered charity which represents the interests of people with a colostomy. The CA offers support, reassurance and practical information to anyone who may be about to have, or already has a colostomy. The CA provides the following services:

- Support and advice for colostomates, their families and their carers
- Email and 24hr telephone helpline
- Comprehensive advisory helpline
- Quarterly magazine
- Informative literature
- Home or hospital visits for those who need them

CA works closely with stoma nurses to promote colostomy irrigation as an effective means of stoma management. An explanatory DVD is now available for patients and healthcare professionals. Please remember to utilise our support services on an ongoing basis for the benefit of colostomates, their carers and family members.

CA has gone from strength to strength over the past decade and our dedicated volunteers base now stands at over 100 across the UK. Operating a rigorous vetting procedure for potential volunteers - the CA and our website.

We hope you can join us at one of our special celebratory events next year. Look out for further details in *Tidings* and on our website.

0118 939 1537 Email: info@colostomyassociation.org.uk Website: www.colostomyassociation.org.uk

Enterprise House, 95 London Street, Reading RG1 4QA Registered Charity No. 1113471



Sarah Squire

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Soft Convex
generation

Introducing the new NovaLife **Soft Convex**



NEW NovaLife Soft Convex with EasiView viewing option

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With its unique flexible construction, the new NovaLife Soft Convex skin barrier gives a gentle push to help even out peristomal skin, creating an enhanced skin seal for greater comfort and security. It is the flexible and skin-friendly solution that gives a comfortable and reassuring fit.

The new Dansac NovaLife Soft Convex is available in one-piece, both closed and drainable and introduces the new EasiView viewing option to give that extra confidence in a glimpse.

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My current appliance is _____

Ileostomy Colostomy

Simply fill in the reply coupon, pop it in an envelope marked: **FREEPOST DANSAC**. No stamp or further address details are required.

Name: _____

Address: _____

Postcode: _____

Tel: _____

Email: _____

Ref:1080

NEWS FROM THE OFFICE

Following their meeting, the **Colostomy Association** Trustees show their support for Save the Children's Christmas Jumper Day.

Back L-R: Caroline Emeny; Monty Taylor (Chairman); Sarah Squire; Alfred Levy; Ernie Hulme (Vice-Chairman).

Front L-R: Trevor Andrews.



Sue Hale writes: Happy New Year everyone! In January we'll start celebrating our special 10th anniversary year and we look forward to sharing our success with you. During the year we'll be busy raising our profile with the general public to maximise the publicity this special opportunity brings. Further information about our plans can be found on pages 68 and 69, together with a booking form.

Meanwhile, here's some additional information which may be of interest:

Parliamentary Reception

On 11 November, 2014 our Chairman, Monty Taylor, attended the Charity Aid Foundation's Parliamentary Reception running through the GivingTuesday.org.uk campaign and he is pictured below with Rob Wilson MP.



The event was very worthwhile and gave our Chairman an opportunity to speak with

Members of Parliament and network with other charities. Our aim has always been to campaign for the rights of ostomates with MPs and this event has given us the impetus to do so with renewed vigour.

ONGOING: Toilet Cubicle Campaign

In the last edition of *Tidings* we announced our campaign to ensure toilets in stations across the UK are ostomate-friendly. Our campaign is already achieving success – we spoke to Hitachi Rail Europe Ltd, the company which is producing the next generation trains for both the East Coast Line and First Great Western about the toilet cubicle requirements of ostomates. Thanks to our conversation with Hitachi Rail they plan to ensure that a door/wall hook, shelf and sanitary bin will be included in all their train toilet cubicles – making long-distance train journeys more pleasant for ostomates. Additionally, hooks have since been installed in the toilets at Reading station – our local station – so First Great Western are definitely taking note.



As a result of our previous article in *Tidings*, one supporter kindly took the time to write in to say there were no hooks in the toilets at Legoland. We've since written to Legoland to ask them to consider installing toilet door hooks and have received a positive response.

If you happen to visit in coming months, please let us know if they have since appeared! Additionally, if you happen to know of any other locations where toilet cubicle door hooks do not exist, please get in touch so that we can contact the organisation/s concerned as part of our ongoing campaign. This could make a big difference to thousands of ostomates across the country. Thanks so much!

NEW! The CA's 'Poo Taboo' video

Colostomy Association Trustee, Trevor Andrews, a senior lecturer in Marketing has produced a light-hearted short video clip which can be viewed on YouTube at:

<http://youtu.be/SfsqOZZqj0A>

This now forms part of a structured marketing plan which focuses on raising our profile and on our 10th anniversary plans. Please help us make this footage go "viral" to increase awareness of the **Colostomy Association** by sharing it with your friends and family. Many thanks.

CONTINUED ON PAGE 41, COLUMN 1





RELAX

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SecuriCare's award-winning home delivery service is based on a philosophy of putting you first. We can deliver all makes of stoma products and accessories to your house, free of charge, at a time that suits you. We provide personal customisation, even for difficult stoma shapes, with our ultrasonic cutting machine, and a choice of wipe and bag disposal systems. The personal touch doesn't stop there – we'll give you your own dedicated contact so you can speak to the same person every time you call us. Our friendly and supportive staff have over 20 years' experience of giving patients with stoma needs expert advice, and providing a convenient and discreet service.

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To arrange a delivery or to find out more visit www.securicaremedical.co.uk or call 0800 585 125.

www.securicaremedical.co.uk

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SecuriCare[®]
Putting you first

NEWS FROM THE OFFICE

CONTINUED FROM PAGE 39, COLUMN 3

PLEASE HELP! Request for Life Stories

Do you have an interesting life experience? Would you like to share your story with the wider public?



Our new marketing communications officer, **Niall Norbury**, would like people to come forward with interesting and unique stories of their life with a colostomy.

This will help us to raise public awareness in a variety of new ways such as publishing people's life stories in national magazines and newspapers.

We need your help to achieve this! Please consider sharing your story as it will help put an end to the 'poo taboo' and improve public perceptions of living life with a stoma. Niall will be working on a large range of marketing activities and he hopes to hear from you soon! Many thanks.

If you would like to share your story with others and are happy to have it published in the wider domain then please email Niall at:

niall.norbury@colostomyassociation.org.uk or phone the office on: **0118 939 1537**.

NEW! Colostomy Association now on Twitter

The **Colostomy Association** has finally joined Twitter, thanks to Niall. Be sure to follow us to keep up to date on the latest

news, information and events from the **Colostomy Association** – our Twitter handle is **@ColostomyAssoc**

If you have a story, event or piece of news you would like us to share via our Twitter page then please either tweet us or email Niall at:

niall.norbury@colostomyassociation.org.uk to help us spread the word.

When Mum Has a Stoma

This booklet explains to children what happens to mum and it could be a useful tool for parents struggling to have open discussions about the topic. Please refer to the link below for more information as copies are no longer available in print:

http://www.coloplast.fi/avanne/Topics/Lifestyle/WhenMumHasAStoma/Documents/When_mum_has_a_stoma.pdf

Volunteer Event

In November 2014 over 20 of our wonderful volunteers attended a special training weekend in Chester. It was an opportunity for them to refresh their skills, socialise together and learn more about stoma care from qualified healthcare professionals. Feedback from our volunteers has been excellent and a big thank you goes to ConvaTec for sponsoring this invaluable event.

New volunteers are not currently being recruited as we already have over 100 dedicated UK wide colostomates in our team but watch this space for future announcements should the situation change.

24 Hour Helpline

It's amazing how many people still aren't aware of our 24 hour helpline, which runs 365 days a year. Please call us whenever you need help or support! We handle thousands of calls each year and always have time to offer help with specific concerns, answer general queries, provide literature, arrange a follow up call from a fellow ostomate or simply lend a listening ear. No question is too silly to ask – so telephone our helpline on **0800 328 4257** today!

Photographs

Please remember the following when taking photographs for use with your stories in *Tidings*:

- high resolution (300dpi about 10Mb) photographs are required for print in magazines, so some mobile phones are not suitable;
- portrait photographs (upright) rather than landscape (length ways) are better for the front cover – the pictures still need to be hi-res of 300dpi and about 10Mb – these pictures are around 4,000 pixels wide and 6,000 pixels high;
- photographs that are a one off (such as those that appeared with Tara's story in the Autumn) cannot be restaged so we occasionally have to use some that are of a poorer quality.

Your stories are all unique and often incredibly emotive to read so please continue to share them with us and remember to take good quality, high resolution photographs to accompany them! The editorial team hope to hear from you soon.

A BIG Thank you

A special thank you goes to all our supporters and volunteers for helping us make the **Colostomy Association** what it is today!

With kindest wishes for health and happiness in 2015, from everyone in the admin team and the Board of Trustees.

Coming up in future Issues

- ❖ Reversal operations
- ❖ Lasting legacies
- ❖ Wet Stomas
- ❖ Employment rights
- ❖ A week in the office
- ❖ Plus 10th anniversary raffle tickets



Addendum to Wills Article

In the Autumn 2014 edition of our *Tidings* magazine, Rachel Fuller wrote about the importance of writing a Will. Here's some additional information which may be of help when appointing an executor of your Will.

Careful thought needs to be given on whom to appoint as executor as they will be responsible for overseeing all of the proceedings after you've passed away. This would normally be a person you trust such as a close friend or relative.

If they happen to pass away before you die, it will be left to the remaining executors to administer the estate or you should consider appointing a substitute executor if you have only appointed one in the first instance. If your one and only executor dies

before you do and you have not appointed a substitute executor, it would be up to your 'next of kin' to take on the role.

Sometimes the solicitor drawing up your Will might suggest they (or the partners in their firm) could be your executor. However, they will charge fees at their normal rate and some firms charge a percentage fee on top, based on the value of the estate.

These fees are charged even to administer a small estate so this is not the best option and should ideally be avoided.

However, if you really do not have any friends or relatives to administer the estate your only choice would be to appoint a solicitor to act as the executor but that is really the **ONLY** time this should happen. In all other cases the spouse and/or a member

of the immediate family or a friend/s would be appointed as an executor.

If your estate is very simple, an application for a Grant of Probate can be a fairly simple process for your executor and it may be unnecessary for a solicitor to be involved as the Probate Registry are very helpful in guiding executors on how the probate process works. If however the estate is slightly more complicated, it may be worth involving a solicitor – who need not be the one that prepared the Will. It could be any solicitor of your executor's choosing.

Please don't let the selection of a suitable executor put you off preparing a Will as it is important that everyone has one. Think of your loved ones. The benefits were outlined in the previous edition of *Tiding* and it is far better to have a Will than to die *intestate!*

Get your chance to win with the 500 Club

Simply complete and cut out this standing order mandate, as soon as possible and return it to:

Colostomy Association,
Enterprise House
95 London Street
Reading
RG1 4QA

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

Colostomy Association:
Lottery Licence no. LOT000141

500 Club entry form

My Details:

Title: Name: Surname:

Address:

Postcode:

Telephone number: Email:

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

To the Manager: (Bank or Building Society)

Bank Address: Postcode:

Name(s) of Account holder(s):

Account number: Sort code:

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

Account name: **500 Club** Account No: **89252314** Sort code: **60-17-21**

the sum of **£24.00** amount in words: **Twenty four pounds only** per year

Quoting reference: **500 Club**

Date of first payment: **(at least one month from submission)**
and thereafter on the same day every year until further notice.

Name: (IN CAPITALS)

Signature: **Date:** / /2015

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

We need YOU! Fundraising is an immensely important source of income for the Colostomy Association as we rely heavily on donations. Help us continue to provide support to ostomates and their families 24 hours a day, 365 days a year.

Donations
When sending your donations please don't forget to include your contact details.
Thank you!

Fundraising Focus

We're always amazed at the efforts of our supporters and very much appreciate the imaginative ways people fundraise. Some of their activities and general donations are listed here, along with other ways of raising funds for us including an opportunity to take part in the Royal Berkshire 10k run in May.

General donations

Money boxes are a great way of raising awareness of our Charity while also encouraging the donation of vital funds.

- ❖ Over **£50** was donated by customers of Barclays Bank in Gadbrook Park, Northwich. Arranged by Suzanne Done, the wife of a **Colostomy Association** volunteer, Chris Done.
- ❖ St Mary Magdalene Parish Church raised **£245** at a coffee morning last autumn.
- ❖ Shropshire BOTS support group raised **£70** in a raffle with only 14-15 people in attendance!
- ❖ Allan Grady kindly donated **£275** in lieu of presents at his 65th birthday party.
- ❖ Rosemary Whitebread gave **£60** in October 2014 and said: "Tidings has helped me regain control of my life which had turned into a nightmare after five terrible operations. Thanks to the fantastic irrigation articles, my stoma care nurse helped me try this out and it's given me back my quality of life."
- ❖ The owners of a caravan park in Devon organised an ice bucket challenge and raised **£350**. After consulting with our President, Ian Daniels (who had performed life saving surgery on Joan Jeffery) it was felt the funds should come to us! Joan's sons arranged the event as a thank you to Ian for saving their mother's life as she had only been given four weeks to live.
- ❖ In November, Deutsche Bank canvassed its pensioners to see whether they'd like to receive a £90 Christmas hamper or donate the funds to charity. This resulted in 55 pensioners kindly voting to donate the funds and our Charity was selected to receive the total of **£5,445!** The generosity of the Deutsche Bank's pensioners is very much appreciated.

Just Giving Fundraisers

Martin Daniels ran the *Love Luton Half Marathon* in October 2014 and raised **£260** in support of his father, Gary Daniels.

Several JustGiving supporters got involved in the *ice bucket* challenge and raised funds for our charity with donations arriving via www.justgiving.com

Thank you so much to everyone mentioned above and to those we've not got room here to publicly thank too!

London Marathon

A big thank you goes to everyone who kindly offered to run this major event for us on 26th April this year. We've now selected a lucky person to run for the **Colostomy Association** and will include details of how to sponsor our runner in the Spring edition of *Tidings*. We'll try to obtain more places for 2016 so that several more of our supporters can participate on our behalf next year so watch this space!

Runners Wanted! Royal Berkshire 10k Run – 17 May 2015

Would you like to run this 10k race for the **Colostomy Association**? We've been given five free places this year so if you'd like to fundraise for us please get in touch. Each runner will receive a free event T-shirt from the organiser. It starts in Reading at 10.30am. The route is flat and scenic and ideal for personal best chasers or first time runners! More information can be found at www.royalberkshire10k.com

NEW! Give a Car

Giveacar is a not-for-profit social enterprise that can turn an old car into cash for our charity. This is often a very convenient way to dispose of a car which has very little

trade-in value against another car being bought at a garage for instance.

Giveacar will arrange free collection, then either sell your car at auction or scrap it with the proceeds raised going to the **Colostomy Association**. Giveacar has won several awards and has already supported over 1,000 charities. Using a nationwide network of breakers yards and salvage partners, they have handled the auction and disposal of over 8,000 vehicles so know how to raise the best donation possible whether the car is in perfect condition or not.

They arrange collection at a convenient time so please help us benefit from this new way of fundraising. For more information or to arrange the free collection of your car please telephone **020 7736 4242** or go to: www.giveacar.co.uk/charities/colostomy-association

NEW! Clothing Collections

Look out for **Colostomy Association** clothing collection bags coming through your doors this Spring as they're being distributed by a company who estimate they will be giving us more than £750 per month.

In addition, if you live in London, Essex, Kent, Hertfordshire and Suffolk areas, you can put your unwanted clothing in your own bags or boxes and then telephone **0844 879 4417** and arrange for your clothing collections to be picked up at a convenient time and place for you.

Alternatively, you can book your collection on their website; an operator will call and arrange for a time and place for picking up your items. Visit their website at: <http://icollectclothes.co.uk>

Please help us make this new scheme a huge success so please save up your unwanted clothing items and donate them in this way!!

CONTINUED ON PAGE 45, COLUMN 1

A Hollister Technology

New Soft Convex Skin Barrier

Designed with the Individual in Mind

Introducing the new range of **Moderma Flex** closed one-piece pouches with a new diamond shaped Soft Convex SoftFlex skin barrier. Designed especially for individuals that will benefit from the flexibility and conformability that Hollister soft convexity offers.

SoftFlex skin barrier formulation

Gentle on the skin, the SoftFlex skin barrier is thin and flexible

Diamond shaped barrier

Offers greater adhesive coverage on either side of the stoma for added security

Soft and flexible convexity

Designed to conform to each individuals body shape for comfort and security

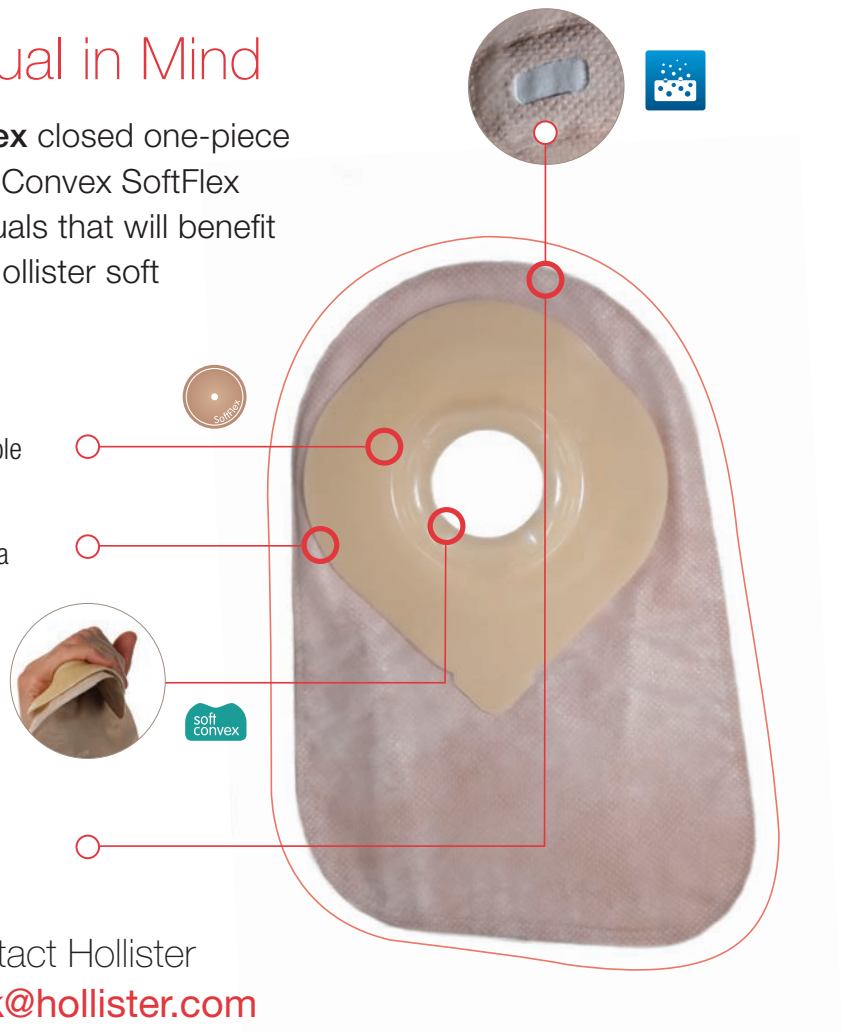
AF300 filter

Generous air flow, coupled with an odour-eliminating carbon element, help reduce pouch ballooning and odour.

To request FREE samples, please contact Hollister at **0800 521 377** or email **samples.uk@hollister.com**

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NEW! Floral Bouquets

Clare Florists have kindly agreed to produce a **Colostomy Association** bouquet and these can be ordered by telephoning: **0800 073 7676**. Our bouquet is a beautiful mixture of purple, white and green flowers – containing irises or course! For every bouquet sold, they will donate **£3.49** to us so please support this new fundraising initiative if you can – and don't forget Mother's Day on Sunday 15 March 2015! For more information please visit www.clareflorist.co.uk

In Memory

Following a bereavement the last thing people probably think about is charitable donations from family or friends in memory of their loved one. Memory Giving allows people to make an online donation in lieu of funeral flowers for instance and can easily be promoted by the funeral directors.

For more information about this alternative way of donating in memory of your loved one, please visit: www.memorygiving.com



Annual Cake Sale



Each November **Colostomy Association** Trustee Caroline Emeny runs a cake sale in

her lovely home village in Suffolk. The popularity of this event grows year on year. This year Caroline and her dedicated team of cake bakers and sellers raised a whopping **£850!** Some of the beautifully decorated cakes which were donated are shown above.

Used Stamps

Please note the address for used stamps has changed to that given below but remember to mark the envelope "CA" so they are allocated to our pot of funds.

CA
c/o Fundraising Stamps Ltd
59 Mitre Copse
Bishopstoke
Eastleigh
SO50 8QE

Significant funds are being donated by this company as a result of our supporters sending stamps there, so please continue

CA NEWS FROM THE OFFICE
 to send your unused stamps to our contact. If they are separated out into UK and foreign they're worth even more money too – up to £20 per kilo in fact!



It is important that the stamp's perforations are not damaged so please try to keep any tears or cuts away from the edge of the stamp. Ideally a minimum of 1cm should remain all

the way around.

FREE post envelopes are now available in two sizes that are pre-addressed and pre-paid:

- 1 A5 – each holds up to 250 grams with the envelopes packed up to 25 mm or 1" thick;
- 2 A3 – each holds up to 2 kilos.

The envelopes can either be ordered online, via email or by telephone. Full details are given below:

Telephone: **07599 830 966**

Email: fundraisingstamps@btinternet.com

Website: www.fundraisingstamps.com

Hopefully you've all kept the stamps off your Christmas card envelopes! Much appreciated.

Win **BIG** with our 500 club prize draw

The 500 club is a way of raising vital funds for the **Colostomy Association** and also gives you the chance to win cash prizes ranging from **£25 to £1,000**.

For only £24 per year, you will be entered into a quarterly draw for cash

prizes of up to £500, £250, 3 x £100, 3 x £50 and 3 x £25.

At the end of each year a further prize of £1,000 is awarded.

Draws will take place at the end of March, June, September and December and winners will be notified shortly thereafter.

Membership is restricted to the first 500 applicants so don't delay.



For more information contact us on **0118 939 1537** or download the form: www.colostomyassociation.org.uk

500 Club September 2014 Draw Winners!

Anonymous	£ 311.00
Miss L Ferris	£ 155.50
Mr P Foulger	£ 62.20
Mrs B J Kneller	£ 62.20
Mr K Brennan	£ 62.20
Mr J Fulluck	£ 31.10
Mrs D Reddick	£ 31.10
Anonymous	£ 31.10
Anonymous	£ 15.55
Mr C R Oram	£ 15.55
Mr P Grogan	£ 15.55

NOTE:

The following people kindly donated part of their winnings back to the **Colostomy Association**: **Mr J Fulluck £25; Anonymous £100; Miss L Ferris £25; Mrs B J Kneller £12.20; Mrs D Reddick £10; and Mr C R Oram £15.**

CLINICAL RESPECT



Fittleworth is a specialist in home dispensary for ostomy, urology and wound care that promises not to change your prescription, except with the consent of the prescribing nurse or GP. We call this **Clinical Respect**.

- We do not amend, substitute or add anything to your prescription unless prior approval has been received from your prescriber/clinician
- We do not `sell` to you or suggest accessories should be added
- We support you and your care by delivering a quality prescription home delivery service ensuring all regulatory requirements are adhered to
- We work closely with the clinician complying with any instructions issued
- We recognise the prescribing authority and our professional responsibilities to both you and the clinician
- We recognise the cost pressure on the NHS and work with your clinician to ensure the NHS receives value for money and a quality dispensing service
- We comply with the NHS appliance dispensing regulations
- All Information Governance and Data Protection regulations are audited and adhered to

For further information on our service or to register,
please contact us on **0800 378 846** or visit **www.fittleworth.com**

Simply... a secure home delivery service



Ostomy Lifestyle update

Sue Hatton continues to head up the Board of eight Trustees as Chairman and the committee meet regularly to discuss their future plans and existing projects.

OstomyAid

Sadly in the summer the landlord of their OstomyAid project gave notice to vacate the premises in Bracknell which had been leased for several years.

This meant that this incredibly worthwhile project has had to be put on hold and no further surplus supplies are being accepted until the project can be relaunched.

A working party is in place to raise funds to cover the cost of warehouse premises, a paid member of staff, volunteer travel costs and associated overheads. It is hoped that OstomyAid will relaunch later in the year so look out for further updates in future editions of *Tidings*. In the meantime, if you have any unwanted supplies to donate, please contact the following organisations:

Jacob's Well

2 Lady Gate, Beverley, East Yorkshire, HU17 8BH. Tel: 01482 881 162, Email: office@thejacobswell.org

Christian Response to Eastern Europe

3 Lumley Close, Kenton, Devon, EX6 8HT. Tel: 01626 891 945, Email: hugh@cr2ee.org.uk

Hospices of Hope— who have a network of shops in Kent, Surrey and parts of Scotland

11 High Street, Otford, Kent, TN14 5PG
Tel: 01959 525 110,
Email: office@hospicesofhope.co.uk

Please think before disposing of unused products as it does waste precious NHS funding – if they can be used, please try to do so.

Please also bear in mind that it may only cost around £10 to post a parcel off after removing the cardboard packaging, but these supplies will make an immense difference to people.

Ostomates living in developing countries either have no stoma products whatsoever (making do with baked bean tins and string) or only have access to very poor quality/expensive pouches. They urgently need your help.

The Nuts & Bolts of Running a Support Group

The BIG Lottery funded training course for support group organisers and those wishing to set up a new local stoma support group across England will soon cease as the funding expires in March 2015.

Helen Bracey who runs the *Nuts & Bolts* course says: "This course is part of a four year project which has been funded by the National Lottery through the Big Lottery Fund. The funding comes to an end soon, so please get in touch now if you'd like to take advantage of this interactive and informative free training course.

"Following attendance at the course, more than 150 people have either gathered the resources to set a new group up, or have revitalised their existing group, greatly benefiting hundreds more people. The project simply could not have been done without the lottery funding."

The sessions cover the essential elements involved in running an effective support group for people with stomas and include:

- learning about the different types of stoma and how they are formed;
- learning how to promote a support group effectively, making use of the internet and 'on the ground' advertising;



LOTTERY FUNDED

SUPPORT OSTOMY LIFESTYLE

- discovering the ingredients of a good group meeting;
- learning how to handle issues such as conflict and bereavement within the group;
- establishing financial security for a group;
- learning how to ensure there is adequate support at organiser level; and
- developing practical skills to help manage the administration of a group, including data protection considerations.

Lunch, refreshments and course materials are provided and up to £50 towards travel expenses can be reimbursed. For those who are unable to make the workshops in person, Helen is able to offer remote delivery of this course via Skype group conference calls.

Workshops for support group meetings

Another part of the BIG Lottery funded project is the delivery of one hour workshop sessions at support group meetings.

These workshops cover a variety of topics including: How and why stomas are made (featuring the ever-popular Anatomy Apron); Healthy Eating; Travel and Body Image.

The workshops are fun and informal and are designed to stimulate discussion. If you would like to book a workshop for one of your group meetings before the end of March 2015, get in touch!



Please contact Helen if you are interested in attending a *Nuts & Bolts* course in your area, or booking a workshop at one of your group meetings by emailing: training@ostomylifestyle.org or calling Helen on **07868 616374**.

For more information please refer to their website at: www.ostomylifestyle.org

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Gentle, quiet, convenient and effective, Peel-Easy and Clinifilm combine everything that feels good in colostomy skincare. Both are available as handy wipes, or an advanced bag-in-can spray which can even be used upside-down.

With no cold, noisy propellants, you just get soothing protection or gentle adhesive removal.

And with our free samples, you'll really feel good!

Easier dressing removal

Thorough, painless removal of medical adhesives

Skin is left ready for the next dressing

Ideal for sensitive or fragile skin

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Silicone protection for sensitive skin

Protects from body fluids and solids

Helps prevent skin damage from stoma pouch adhesives



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Unit 2002 Elland Close, Wingates Industrial Estate,
Westhoughton, Bolton, BL5 3XE

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Tel: **01942 816184** Email: info@mapharmachem.co.uk

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"This was a very difficult time and was a lot to take in"

We're just back from a brilliant weekend away in Berwick-upon-Tweed, where we said hello to three 'old' families and welcomed eight new families. The weather was really kind to us and Saturday morning saw us on the beach, launching rockets and poking around in rock pools. One of our trustees was spotted sitting making a sandcastle! We've wanted to do something further north for a long time, so this was a great opportunity to spread our wings that little bit further.

We've had our family helpline since the first Breakaway weekend back 2007 and, while it's been incredibly important to our families, we realised earlier this year that the world was changing. People no longer pick up the phone to ring a number, but pick up their phone and search Google or Facebook. We knew that we needed to respond to the changing needs of our families, and so we set up two closed Facebook groups. One is for the under 18s as a safe space to talk to other children with similar conditions. The other is for families, where parents, grandparents and other family members can ask questions, and get the support that they need when they need

it. We've found that this group is busiest after 9pm as that's when the children are finally in bed, the household chores are done, and mum and dad can sit down and have a bit of 'me' time. The group is moderated by a team of admin, all of whom have personal experience of living with a child with a bladder/bowel condition, and have received dedicated training. We have nearly 350 members now, and amazingly for a Facebook group, we've not had any falling outs at all!



A mum writes: "My daughter was born in 2012 and after her birth she was diagnosed with an anorectal malformation called *cloaca*, meaning she had no urethra, vaginal opening or anal opening, but a common channel connected to her bladder, womb and bowel. This was a very difficult time and was a lot to take in. My daughter had surgery two days after her birth to fashion a stoma to allow stool to pass. A few months after her birth I joined the **Colostomy Association's** Facebook group and found out about Breakaway through them. It has been so helpful. Just to find other parents with children that have similar conditions to yours is so reassuring. The Breakaway Facebook group is especially helpful because you can be up at 3am with your child's needs and need

someone to talk to and there will be other parents around to ease your angst, make you laugh or talk to you through your tears. You can just read and learn about how others do things, or ask for an opinion and advice. It means so much to have people who truly understand you and how you need to live your life."

Tracey says: "Breakaway did something amazing for us. It made us smile again and made us realise we're not the only family going through this stoma stuff. Breakaway allowed us to have fun, to do amazing activities and laugh our socks off. Breakaway has opened a dark door into a world of fun and happiness, it's allowed us to meet families that actually fully understand the grief and hard times you're having and turn that into a close friendship of a new family. The Facebook group has been a lifesaver. It's there when I have a question about his ACE, there when I'm having a bad day and need to talk to someone who understands, but it's also there when I want to shout from the rooftops about how proud I am of my son and all he puts up with. Without Breakaway our lives would be very dark and possibly splitting as we were just filled with sadness. Thank you Breakaway from all our hearts. We owe you our happiness."



More information about Breakaway Foundation.

Donate online via:
<http://www.justgiving.com/breakawayvisits>

Write to us or send a donation to:
Breakaway Foundation
PO BOX 7982
Swadlincote
DE11 1FB

Telephone:
01283 240253
Email:
info@breakawayfoundation.org.uk
Web:
www.breakawayfoundation.org.uk



Our kindest pouch yet

The new extensive range of Aura™ pouches feature our tried and tested skin-friendly Hyperflex® hydrocolloid flange, but now with the added benefit of medical grade Manuka honey. The inclusion of Manuka honey in our Hyperflex® hydrocolloid may help to promote healthy skin around the stoma.

New Aura™ also has an accurate cutting guide for a perfect fit, Easy2peel™ tab for easy removal, a super-soft water-repellent cover for outstanding comfort and a new Dual-Carb®2 and Dual-Carb®i filter for better odour management and reduced leakage.

Available in a range of sizes and in Closed, Drainable, Urostomy and Stoma cap variants, the new Aura™ with Manuka honey is our most comfortable, skin-friendly pouch yet.

Find out more at www.clinimed.co.uk



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Mr/Mrs/Miss/Ms: _____ Initials: _____ Surname: _____ Address: _____

Postcode: _____

Tel.No.: _____ Email: _____

I understand that this request will be handled by CliniMed Limited or SecuriCare (Medical) Limited. I would like my details to be kept on file, so that I can be kept up to date with information about relevant new products and services.

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Junior Ostomy Support Helpline (JOSH)



The new parent helpline called JOSH is now available for parents or carers of children with a bowel or bladder diversion/dysfunction. A select group of parents/carers have been trained at our offices by a paediatric stoma care nurse and our JOSH helpliners are ready to take calls.

This dedicated team of volunteers have a wide range of experience surrounding children's continence issues and they are helping other families in similar situations. This is not a medical advice service and anyone with medical queries is directed back to their health professional.

This service operates through the **Colostomy Association's** 24 hour helpline and our operators pass on referrals by matching them to one of the JOSH parents.

It provides a vital lifeline to carers when they are at their most vulnerable and also redirects callers to Breakaway or Diversions where appropriate.



Pictured here with Blake Beckford is Wendy Hetherington (**Colostomy Association** Trustee) and Jenny Shimmin who volunteered to man the JOSH stand at its launch this autumn at the Association of Stoma Care Nurses (ASCN) conference in Harrogate.

A big THANK YOU goes to all our lovely **Colostomy Association** helpliners who field any JOSH calls. It's much appreciated.

Your Travel Checklist

On top of all the normal precautions, like making sure your travel documents are in order, take copies of important documents with you in case the originals get lost or stolen.

The ostomate needs to remember to:

- take sufficient supplies for your stay;
- take all supplies and travel stoma kit as hand luggage;
- ask the airline in advance if you need extra hand baggage for your supplies;
- 'check in' online 24 hours before departure to secure your preferred seat;
- avoid food and drink the day before you are to travel that are likely to cause upset or excessive wind;
- take medication to firm up or loosen output;
- carry your Travel Certificate with you especially when passing through immigration or security areas;
- take some form of electrolyte replacement solution in case you become dehydrated;
- drink bottled water in foreign countries, avoid ice in drinks and use bottled or boiled water to clean around your stoma area; and
- store your supplies in a cool place, out of direct sunlight.

CA Booklets, Leaflets and Factsheets are available



Simply contact:

General Enquiries:

0118 939 1537

Monday to Thursday

9am – 5pm and

Friday 9am – 3pm

or

E-mail:

cass@colostomyassociation.org.uk

or download from our

Website:

www.colostomyassociation.org.uk



Sophie Medlin registered dietitian and lecturer in dietetics at Plymouth University provides advice on how to lose weight. She considers why some ostomates may find this difficult and suggests solutions.

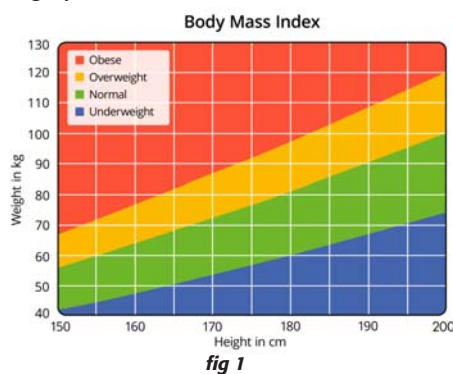
Losing those extra pounds after Christmas can be difficult when you have a stoma. Many people gain unwanted weight following stoma surgery due to changes made to their diet in an effort to control their output.

A good way of assessing whether you need to lose weight is to calculate your **Body Mass Index (BMI)**. This measures how heavy you are in relation to your height and can be calculated using the equation: Height x height (in metres) divided by weight (in kilograms).

- If your BMI is below 18.5 (blue area, fig 1) you are underweight and should not be looking to lose weight. If you are under weight and are struggling with your appetite speak to your stoma nurse or GP who can support you and may refer you to a dietitian.
- If your BMI is between 18.5 and 24.5 (green area, fig 1) you are within the healthy range, which shows that you are a healthy weight for your height. However, it is still important to eat a healthy, balanced diet and include physical activity in your daily life.
- If your BMI is 25.0 or more (yellow area, fig 1) this is above the ideal range, which means that you are heavier than is healthy for someone of your height. Excess weight

can put you at increased risk of heart disease, stroke and type 2 diabetes, so losing your excess weight is advisable.

You may be interested to know what your weight was prior to your stoma formation; your stoma nurse or consultant should have a record of this. Gaining excessive weight following stoma formation can lead to stomal retraction (where the stoma sinks into a skin fold or dip in the abdomen) and hernias which can cause complications fitting devices and may require further surgery.



Unfortunately there isn't an easy solution to losing weight. Despite what you may read in magazines or on the Internet, the only way of successfully managing your weight for good is making small changes to your lifestyle to accommodate more physical activity and make healthier food choices.

While fad diets may reduce your weight quicker, keeping it off is another matter. Sometimes it seems that all 'healthy' foods are high in fibre and can cause unwanted side effects. While high fibre foods are good

for keeping you fuller longer, they are not the be all and end all of reducing your weight and, therefore, people with stomas should still be able to reduce their weight successfully without adverse consequences.

It is worth being aware of how our body manages energy from our food as this can help to apply some logic to the battle of weight loss. When we eat, the energy (measured as calories) from our food is either used by our muscles because we're active, or stored as fat for when we exercise or don't eat.

In our modern society where our jobs are sedentary and we don't have to catch or dig up our own food, we require less energy and easy access to energy dense food means we have a tendency to overeat. Each pound of stored fat is the equivalent to around 3,500 calories, this means that you need to have 500 calories less per day to lose 1 pound of fat per week. The healthiest way to do this is to increase your exercise so that you burn more energy and reduce your calorie intake from food in a sustainable way.

There has been lot of writing in the press recently about the best way to lose weight and debate around whether it is fat or sugar that is causing us to consume excess calories. In the UK we have always believed that fat is the cause of weight gain and is the danger to our health. In America, they believe that sugar or carbohydrate is the main factor. So far, the debate has not been resolved. However, we do know from scientific research that both sugar and fat contribute to weight gain.

Examining your own diet for the amount of fat and sugar you consume is a good start to tackling your weight.

Sugar: when we talk about 'sugar' in this context, we are talking about sugar in its simplest form – table sugar, right up to complicated sugars usually referred to as carbohydrates.

Looking for simple sugars in the diet seems easy, until you begin to look at the ingredients lists of convenience and processed foods such as ready meals and even yogurts. It is helpful to consider that a lot of sugar is considered to be over 15g per 100g and a little less than 5g per 100g. Being aware of hidden sugar in your diet may help you to make better food choices. Carbohydrates are foods such as potato, rice, pasta, bread, cakes and pasties. These foods add bulk to our diet and give us energy. However, we have a tendency to overeat them, particularly in the cold winter months. Scientists are discovering that we need much less carbohydrate than we previously thought.

Fats: Recently it has been identified that following a low fat diet generally leads people to have a high carbohydrate diet which as mentioned above is likely to lead to the same, if not worse, health problems. That said, fat is the most concentrated form of energy we consume and therefore if you are trying to reduce your calorie intake, fat is a sensible target as well.

When we talk about fat, we are referring to oils and butter that we visibly add to our foods, visible fat on meat, high fat products such as full fat dairy and more importantly, hidden fat in processed foods that we aren't aware of. Check the labels and bear in mind that a lot of fat is more than 20g per 100g and a little is less than 3g per 100g. Try to choose low fat and sugar products where possible to save on calories.

When we reduce the amount of carbohydrate in our diet we can feel hungry. It is helpful to bulk up on vegetables to compensate for this and sound advice would be to base your meals around a good portion of lean protein such as chicken, fish, red meat or vegetarian protein sources and focus on having 2–3 portions of vegetables with this (not including potatoes), with a small side portion of carbohydrate such as 1–2 tablespoons of rice, 1–2 egg sized potatoes or a slice of bread.

Fruit and vegetables: are also excellent sources of vitamins and minerals and the vast majority are very low in calories and fat. Unfortunately the high fibre content of fruit and vegetables can affect stoma losses and make these foods more difficult to tolerate.

Peeling fruit and vegetables and cooking them well can help with these problems. Root vegetables are usually very well tolerated and it is a great time of year to enjoy them roasted with a seasoned chicken breast.

Portion size: Perhaps your diet and stoma output are in delicate balance and, although you do want to lose weight, you are worried about making any changes due to the risk of unwanted side effects. Or, maybe you feel you are eating the right things and still not losing weight. Reducing your portion size is a fool proof way of reducing your calorie and fat intake, promoting weight loss.

Here are some tips to getting portion in perspective:

- Try a smaller plate – a side plate may help you to control your portions.
- Eat the same foods but ¼ to a ½ less
- Measure out fat and oil to keep the amount you use under control.
- Eat your food slowly and chew every mouthful for longer – this helps you feel fuller quicker.

Alcohol: Alcohol is very high in calories, which have no nutritional benefit. Be aware of the extra calories you could be consuming from alcoholic beverages.

Average calorie content of alcoholic drinks

Bitter:	1 pint = 170kcal
Cider:	
Dry	1 pint = 204kcal
Sweet	1 pint = 238kcal
Premium Lager:	1 pint = 482kcal
Red Wine:	125ml (small) glass = 85kcal
White Wine:	
Dry:	125ml (small) glass = 82kcal
Medium:	125ml (small) glass = 92kcal
Sweet:	125ml (small) glass = 117kcal
Spirits:	per 35ml measure = 66kcal
	(not including a mixer)

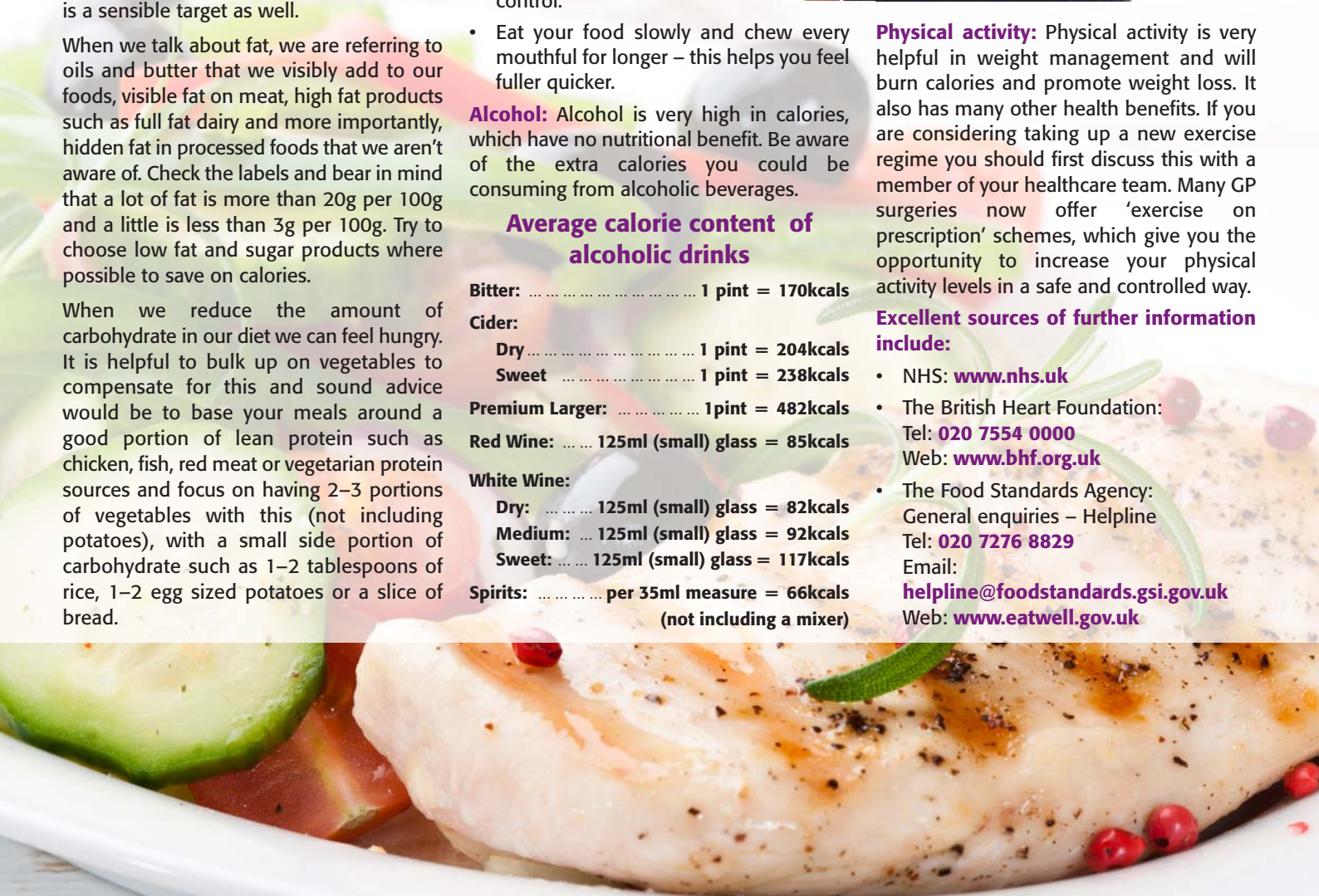


Sophie Medlin

Physical activity: Physical activity is very helpful in weight management and will burn calories and promote weight loss. It also has many other health benefits. If you are considering taking up a new exercise regime you should first discuss this with a member of your healthcare team. Many GP surgeries now offer 'exercise on prescription' schemes, which give you the opportunity to increase your physical activity levels in a safe and controlled way.

Excellent sources of further information include:

- NHS: www.nhs.uk
- The British Heart Foundation: Tel: **020 7554 0000** Web: www.bhf.org.uk
- The Food Standards Agency: General enquiries – Helpline Tel: **020 7276 8829** Email: helpline@foodstandards.gsi.gov.uk Web: www.eatwell.gov.uk



Dear Nurse

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



Q: I have been interested to read the recent articles and letters in Tidings regarding colostomy irrigation. I am now 78 years old and in February 2000, following diagnosis of colon cancer, I had my colostomy. In the following September I started to irrigate and have continued to do so ever since. I have been happy with the freedom that irrigation gives me regarding the management of my stoma. However, my concern now is that I have heard that continuing to irrigate over a long period of time may cause the colon to stretch. This is obviously a worry to me and I would welcome your advice on the likelihood of this happening and whether it is safe to continue with my colostomy irrigation?

A: I have many patients who have successfully irrigated via their colostomy for many, many years without problems. As long as you irrigate using the method you were trained to use by your stoma care nurse, that you do not irrigate more frequently than recommended and use the amount of water recommended you should not have any problems. If any concerns/problems do arise then you should seek a review with your stoma care nurse.

Q: My colostomy is five weeks old and up until now I have only been taking showers, although I know it is possible to take a bath. Pre-colostomy I always liked to use bath oils, which I know are not recommended. Are there any bath products which are suitable? I've looked on various natural product websites, but can't tell whether products are suitable or not.

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

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

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

A: If you are bathing with the pouch off then you need to be careful with products which can irritate the bowel or leave a greasy residue on the skin as they will affect the adhesion of the pouch. However, if you are bathing with the pouch in place then using bath foam should be okay.

Q: I like to think I'm a positive person and have just got on with life since my colostomy last year. Because I was on chemo we couldn't go abroad and I couldn't swim. Now I'm off on holiday and I am so worried about getting into a swimming pool. What I'd like to know is, should my bag come away and sea water or chlorine water get in to my stoma, will it cause me any problems?

A: You should be fine swimming in either a swimming pool or the sea on your holidays. I would advise using a smaller pouch for

when you are swimming and changing it a while before going into the pool to ensure it is well stuck. If you do have a small leak there should be no problem and the water should not actually enter the stoma anyway but you would need to change it immediately. However, there is no reason to believe the pouch will fail you at all. Go on holiday and enjoy yourself and maybe share your experiences with *Tidings* on your return.

Q: I've found that it's possible to get poo/waste out of the stoma by rubbing the skin at the top of the stoma in a circular motion. There's no pain at all. I only do this to loosen and evacuate the stoma so I don't have to keep wiping it until all the waste is out. I wonder if anyone else has tried this? I don't think I'm doing my stoma any harm.

A: This circular rubbing action will actually be stimulating peristalsis, the muscular movement which forces the motion to travel along the bowel. It is used in massage to stimulate bowel action and should not cause any problems as long as you do not over stimulate the bowel which would cause looser more frequent bowel actions, and you do not use undue pressure.

Q: I had my ileostomy in October 2000 (age 58) due to Crohn's disease. Everything has been fine but two years ago a fistula opened on the right side of my stoma. Due to problems I opted for keyhole surgery to have a new stoma and the removal of the fistula, I have since had to wear a convex bag. This year I had a very painful abdominal abscess, which burst and

resulted in another fistula on left hand side of my stoma. My main problem is my stoma always feels very sore and painful. I have tried various creams and potions to no avail. My stoma nurse has not come across this problem so I wonder if you have, and if so can you offer some help.

A: I have a few patients with Crohn's disease who have had fistulae at the side of the stoma and they can be difficult to manage. Using a convex pouch is one way to try to manage them and there are differing levels of convexity. Using the softest convex pouch is best but if this does not work to keep the pouch in place then it may be that a harder convexity is required. Fistulae may heal by themselves but often require surgery to treat them. I presume you will still be on medication to try to control the Crohn's disease. Also a review with your consultant may be of benefit to investigate if you have active Crohn's in the stoma or in the bowel immediately behind it. If so they may need to alter your treatment plan.



Questions posted on Facebook

Q: I sometimes get dull aching pains while sitting but they are crippling when I stand or, in fact, move at all really. I'm told they may be adhesions but how can I be sure it's not a blockage?

A: Adhesions are quite common post operatively and can cause the sort of symptoms you describe. If you had a blockage of the actual bowel you would get abdominal pain, a distended (swollen) bowel with nausea and vomiting. Your output would change, possible to very watery, or your bowel would stop working altogether. If this does occur you will need a review by your GP and possibly an urgent referral to the hospital. If you are concerned with regard to this, a review by your surgeon to discuss potential causes and treatments would be beneficial.

Q: What makes my stoma keep getting bigger? It started as 30mm, now it is 53mm. Is it my hernia or is it constipation?

A: Constipation can cause short term increase in the size of the stoma but it is more likely to be due to the parastomal hernia. This can cause the size of the stoma to increase over a period of time and can be difficult to handle. It may be worth a review with your consultant to

see if a surgical repair of the hernia is a possibility. Or you could visit your stoma care nurse to be measured for an abdominal support belt to try to support the hernia. This would not repair the parastomal hernia but may help to support it and prevent it getting worse.



Editors Comment

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

If so write in and tell us:

**The Editor
Colostomy Association
Enterprise House
95 London Street
Reading RG1 4QA**

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

Photo ID Card

The CA photo ID card is proving very popular as it can be useful if challenged when entering or exiting accessible toilet facilities.

If you would like to apply for a Photo ID card, please complete the form opposite and return it to the CA for processing with the various enclosures listed below:

- A copy of your prescription or delivery note as proof of eligibility
- Passport photo x 1
- Payment – cheque

Note: Payment can be taken over the telephone if preferred.

Alternatively, the form can be downloaded from our website:
www.colostomyassociation.org.uk

Please allow 10-14 days for delivery – thank you

National Key Scheme (NKS) Radar Key and Photo Identity Card

To obtain a **key or a photo identity card** please **complete the form and declaration**. Make your **cheque payable to the Colostomy Association**. Return all required items to: **Enterprise House, 95 London Street, Reading, Berkshire RG1 4QA**

(If you have any queries please contact the admin team at the CA office via the following methods: Telephone: **0118 939 1537** or Email: **cass@colostomyassociation.org.uk**)

National Key Scheme - Key and photo ID card purchase

Title: _____

Name: _____

Address: _____

Postcode: _____

Tel: _____

Email: _____

DECLARATION: I declare that the individual named above is chronically sick, has a disabling condition or has had a bowel or bladder diversion that necessitates the use of disabled toilet facilities. The key is for the personal use of the above named and their designated carer only.

Signature of self or carer: _____ Date: _____ / _____ /2015



- Please **tick** as appropriate:
- I would like to receive a **key** for a charge of **£3.50** (including postage and packing).
- I would also like to receive a **photo ID card** for a charge of **£6.50** (including postage and packing) and enclose a passport photograph.

NOTE: Please send a copy of your prescription/recent delivery note as proof of eligibility and make the cheque payable to: **Colostomy Association**.

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



Readers' writes



Do you have a story to tell, experiences or concerns to share with other ostomates, issues to raise? Maybe you have comments and suggestions about Tidings. Write or e-mail us today. The editorial team looks forward to hearing from you.

Rosemary Brierley

Dear Editor

Not a subject for the faint-hearted, nevertheless the article on rectal stumps in the last issue of *Tidings* was rather interesting. I've had my share of problems in that department and, indeed, it once pushed me back into hospital for what turned out to be a major wash and brush up in there and a thorough examination by my surgeon who said things were inflamed but otherwise fine. He recommended a self-administered wash-out every six weeks or so and recommended using a small washed-out enema bottle, filled with hand-warm water and keeping clean, but not sterile, practices. It seems to do the trick well enough without the need for cumbersome equipment, and is very quick and easy to perform, taking no more than five minutes from start to finish. Before trying this I would suggest getting the OK from a stoma care nurse or surgeon as it may not be suitable in all cases.

A little point concerning the drastic "if all else fails" surgery to close things off permanently. Whilst jiggling with discomfort, I've been known to mutter: "Why on earth didn't he take the whole thing away and close me off for good?" darkly, under my breath as I reach for the comforting tube of *Drapolene*. Well, time moves on and, like many males, what was once a waterfall in the waterworks department is now but a tiny trickle. "Time to take a look at your prostate," said my GP, pulling on her neoprene glove with relish. It was at that point I realised what a valuable little window on the inner workings a bum can be! My lovely GP is far too sweet and nice for me to ask just what she would have done if I'd not had a bum, but I can only imagine a prostate

examination would be difficult. I think it is certainly a factor to consider if one is weighing up the pros and cons of whether or not surgery is the solution to your rectal stump problems?

Yours

Andrew Broadhead

If an ostomate whose rectum has been removed has symptoms of prostate cancer they will have a blood test and an MRI scan. If no symptoms are present only a blood test will be necessary to screen for prostate cancer.

Dear Editor

I was very interested in the article The Rectal Stump in the autumn edition of *Tidings*. Following a spinal injury I had no feeling at all in my bowel. It did not work properly for 50 years and I had to remove the faeces manually. I became severely constipated and so was on a lot of laxatives. I took part in a trial at St Marks Hospital for bowel irrigation via the anus. It was not successful for me, so in 2006 I had an operation to form a loop colostomy which worked very well.

Six months after the operation I had an infection in the rectum so I had to wash out the rectum to remove the mucus which had built up. The stoma nurse came with the equipment and showed me how it was done. I did it through the loop of my stoma. This worked well for some years and then I realised I was no longer able to flush the water through anymore. I thought it must be because my stoma had prolapsed.

Then the stoma nurse gave me another device (as shown in the article) for washing out the rectum through the anus. I use this every month. So far I have done this twice and managed to get the lumps of mucus out.

Also I will add my name to those in support of drainable pouches. I wouldn't want a closed one.

Margaret Florey

A loop stoma has two openings: one through which faeces is passed, the other which leads on to the rectum and anus. At first Margaret washed out the non-functional part of the bowel through this second opening. She now does it through the anus. Before attempting any of these procedures it is important to consult your stoma care nurse or surgeon to check they are suitable for you.

Re – drainable pouches

Like the two colostomates who spoke out in the Autumn edition of *Tidings* I also use a drainable pouch. I wouldn't be without it. My motion is quite loose so I empty it six to eight times a day and like Patricia Fisher I rinse it out, only I use cold water as I find it doesn't smell as much. You can imagine how few pouches I get through. With the drainable I only need to change once or twice a week so a box of 30 can last up to four or five months.

My colostomy was performed six years ago. Before that I was very incontinent and couldn't go anywhere without being well padded and knowing where the nearest toilet was. It was very embarrassing and getting worse so, after a lot of encouragement from the family and work colleagues, I went to the doctors. I was sent to see a surgeon and had a three hour appointment with four different examinations. The surgeon was amazed I had no feelings when he examined me. The end result was a colostomy which I am very grateful for, although it took me six months to adjust to it. I have the odd accident, but thankfully not very often.

Readers' writes

I have been on lots of coach trips. I would like to go back to Tenerife or Majorca, but so far have not plucked up courage to go to the airport.

Hi

I had a colostomy formed for bowel cancer in Feb 2014 (age 37). I have been receiving your excellent magazine for a few months now. In one of the editions I remember reading about Mr Ian Daniels and how he wants to increase awareness of bowel cancer.

I am one of the 'luckier' ones as, even though I required a colostomy, the diagnosis was a Dukes' A cancer [this means the cancer is only in the innermost lining of the colon or rectum or slightly growing into the muscle layer]. The colostomy was due to the tumour lying very low in the rectum, plus it was discovered on the MRI scan that I had suffered a 4th degree tear through childbirth. This made a join and temporary stoma impossible.

I know now that without doubt my cancer would have been caught earlier if I had not 'googled', on many occasions, the term 'bright red blood' which almost always stated that: "if the blood is bright red it is not a concern, it is the darker blood or black stools which can indicate cancer"...and... "bright red blood that is on the paper and not in the stool is normally caused by a fissure or piles" and so on... Due to my cancer being very low the bleeding was bright red and therefore I put it down to piles or a fissure.

I truly believe that people should be advised that ANY bleeding or colour of blood should be investigated. I think this is one big factor that could help a lot of other people out there 'googling' and being reassured that the symptoms are piles.

With many thanks
Helen

Dear Editor

In my husband's issue of *Tidings* I read Bob Williams' article on his colostomy. I was surprised his council advised him to put his waste in dog poop bins. My husband has had a colostomy since 1978 and our council has a service, which delivers yellow medical bags and collects his waste weekly. They have never missed a week in all those years. Our thanks to

Leeds City Council for their marvellous service.

Yours faithfully
J.D.

P.L. *Many local authorities no longer provide a separate collection service for incontinence waste/ stoma bags when they are produced by a healthy person living in their own home. This service is only provided for what in the health profession is known as 'infectious' waste i.e. items containing bodily fluids from a person who has MRSA or hepatitis C or other notifiable infections. Ostomates are advised that appliances should be well wrapped up and disposed of with the normal domestic refuse.*

Dear Editor

I was most interested in your article 'I have a colostomy because...' in your Autumn 2014 edition of *Tidings*. I was given my colostomy 10 years ago because of recto-vaginal pain when passing faeces, due to severe endometriosis. During a colonoscopy it was found that the bowel was affected by adhesions which were causing the severe pain. I was given a high colostomy on the right side as I had previously had my sigmoid colon removed for the same reason.

Five years later my colostomy prolapsed. Much to the amusement of the ward staff, it was treated by putting the prolapsed bowel in a plastic bag and covering it with icing sugar every 3-4 hours to reduce the swelling. Unfortunately this didn't work and I am now the proud owner of an ileostomy.

I will have to have more surgery to fit a suprapubic catheter [a thin tube inserted through the abdomen into the bladder to drain urine]. Because I have adhesions it will have to be open surgery.

I wonder if anyone else has had trouble with endometriosis causing a stoma and a catheter from their bladder going out to the abdomen.

Yours faithfully
A.F.D.

Re: I have a colostomy because... (*Tiding 35 p27*)

I was injured in action, on duty as a district nursing sister. I was to have my first Christmas off duty in 25 years, then I received a telephone call from the superintendent to say trained staff were ringing in sick, would I forfeit my holiday and work. Knowing the necessity and because I loved my work I did. During a visit

to a patient I sustained a serious back injury which required surgery. I was in theatre for nine hours.

Now many years on, I have had several more spinal ops and interventions. I have a calliper and still require assistance walking. I have a colostomy and continuous bladder drainage as all my sphincter muscle were affected due to nerve damage.

This is the reason why I have my colostomy, along with everything else. It is the first time I have spoken out about it, whilst I live with my constant reminders.

Regards
D.B.

Dear Editor

I have had an amazing result following my letter in the last issue of *Tidings*. Twenty-five readers have contacted me, mostly offering their supply of spare filters covers (some offering alternative suggestions to solve the problem of pancaking). Mum has received several years' supply so I am now replying with "thanks, but no thanks!"

Interestingly, one person lives under a mile from me and another lives two miles from Mum (she lives 150 miles from me). Just shows these colostomists are everywhere!

I am very grateful that so many people were so kind and put themselves out to help Mum - I have put a small donation to **Colostomy Association** in the post. Keep up the good work.

Regards
Lynda

Before acting on suggestions from other ostomates you are advised to check with a doctor or stoma care nurse that this course of action is suitable for you.

Thank you for your letters and e-mails. Space permitting, we will print your contribution in the next issue of *Tidings* or we may hold it over for a future issue.

To contribute to the Readers' Writes page:

e-mail:
editor@colostomyassociation.org.uk

or write to:

**The Editor
Colostomy Association, Enterprise House,
95 London Street, Reading RG1 4QA**

Please indicate if you are willing for us to print your full name (or just your first name). In the interest of confidentiality, if you do not give us permission we will publish only your initials. Editing may be required for reasons of clarity or space.

Helpful Ostomy Support Groups & Organisations

- IA The Ileostomy and Internal Pouch Support Group
Freephone: 0800 0184 724
www.iasupport.org
- UA Urostomy Association
Tel: 01889 563 191
www.urostomyassociation.org.uk
- IOA International Ostomy Association
www.ostomyinternational.org
- Stomadata
www.stomadata.com
- Macmillan Cancer Support
Tel: 0808 808 00 00
Mon - Fri: 9am - 8pm
www.macmillan.org.uk
- Mitrofanoff Support
Tel: 01202 937 530
Email: info@mitrofanoffsupport.org.uk
www.mitrofanoffsupport.co.uk
- Crohn's and Colitis UK
Tel: 0845 130 3344
(Mon-Fri 13:00-15:30 and 18:30-21:00)
www.crohnsandcolitis.org.uk
- IBS Network (formerly: The Gut Trust)
Tel: 0114 272 3253
www.theibsnetwork.org
- Bladder and Bowel Foundation (B&BF)
Formerly Incontact and Continence Foundation
General enquiries: 01536 533 255
Web: www.bladderandbowelfoundation.org
- Bowel Cancer UK
Tel: 020 7940 1760
Email: admin@bowelcanceruk.org.uk
Web: www.bowelcanceruk.org.uk
- Beating Bowel Cancer UK
Tel: 08450 719 301 (Lo Call rate)
Web: www.beatingbowelcancer.org
- Gay & Lesbian Ostomates (GLO)
(The United Ostomy Association in 1982 established the Gay and Lesbian Concerns Committee, now called Gay and Lesbian Ostomates (GLO) Network.)
Web: www.glo-uoa.org
- Ostomy Lifestyle
Tel: 0800 731 4264
Email: admin@ostomylifestyle.org
Web: www.ostomylifestyle.org

Stoma Care Patient Open Day event dates

For a comprehensive list of Patient Open Days events, visit the CA website.

Listings are updated throughout year.

If you are not online contact CA on:

0118 939 1537 to find out if there is an event near you.

Note: The Colostomy Association full contact details can be found on Page 7.

SASH

Freephone
0800 389 3111



Ref. No. HB102

Stoma Support & Hernia Belt Ref. No. HB102

The SASH Stoma Support and Hernia Belt is designed and manufactured by an Ostomist and gives support to the muscles surrounding the stoma.

Used by ostomists with a parastomal hernia (a bulging around the stoma) to help prevent muscle damage and enlargement of the hernia.

Eliminates most leakage problems and gives added security and confidence. Ostomists report relief from dull aches and pain in the stoma region when wearing the belt.

Ideal for work, sports, gardening, housework, DIY, or at any time stomach muscles require a firm support.

With support from a Sash belt and periodic consultations with a consultant some Ostomists are delaying, maybe permanently, the need for hernia surgery.



Ref. No. SR103 "The ring of confidence"

Security & Leakage Belt

This lightweight unobtrusive belt is designed to help eliminate leakage problems by holding the adhesive section of the pouch against the skin during all activities.

The belt also gives added security against the pouch becoming detached and will help to support the weight of a full pouch.



Ref. No. SS104

Stoma Shield Ref. No. SS104

The Shield will help protect the stoma from accidental chaffing or knocks.

Ideal for sport, gardening, DIY, housework, manual workers, builders, etc

Sash Medical Ltd.

Woodhouse, Woodside Road, Hockley, Essex SS5 4RU Tel: 0044 (0)1702 206502

Web: www.sashstomabelts.com





Gotta pick a pocket or two...

I am a member of my local sailing club and pay £68 a year so that I can use their clubhouse and sailing facilities including a harbour, training room and bar. It is a great club and has been going 85 years now, having some 800 or so members. It relies on volunteers and attracts a wide range of people from 5 to 95 years of age. Members also get an online magazine published three times a year.

Every four months I also get a copy of *Tidings* dropped through my door, a fact filled and highly professional magazine that makes my sailing club's 'Mainsheets' look rather amateurish. For this I pay £???

The reality is I do not have to pay anything for *Tidings*. The **Colostomy Association** produces 21,000 copies of which 18,900 are sent out to people on our database, with the remainder being distributed to new registrants and stoma care nurses over the course of the following three months.

So, who does pay for *Tidings*? The magazine is funded by advertising and donations from people like you – our supporters.

I would like you to imagine that your employer turned round and asked you to work on the basis of being paid only when there was work to do or when they felt like paying you. Furthermore, they could not guarantee how much work there would be. If you are self employed, I am sure you already appreciate the problems:

- no real idea of how much money you will earn in the year;
- the need to build up a reserve so that if there is no work you can cover your expenses; and
- difficulty planning investments, holidays or development.

The Trustees and the staff of **Colostomy Association** have done a brilliant job over the past ten years of turning very little into a professionally run organisation that is

providing free services to thousands of ostomates throughout the country. The demand for services is ever increasing and there is a need to do more to build a presence in the media and in government circles to defend and protect the current provisions for ostomates, against increasing pressures for reducing government expenditure and making the patient do more and pay more for themselves.

It would be much easier to undertake campaigns if we could have more control over our income. If we could be sure that there was a certain amount of money coming in to cover costs, then the income from your donations and the advertising revenues could be used to develop and grow the **Colostomy Association** and support you whenever help is needed.

One idea is to create an annual fee. If each person receiving *Tidings* paid £15 a year this would bring in £283,500. This amount of money would cover our annual fixed costs of rent, rates, 24 hour helpline, volunteer expenses and administration.

Now some Trustees are concerned that charging a fee would substantially reduce the number of people willing to subscribe to *Tidings* and that this would impact elsewhere. This is understandable and it is likely that some people receiving *Tidings* now will not be willing to pay for it – or indeed could not afford to do so.

However, introducing a fee would mean that the Association would already have some 70% of its average income plan-able each year, creating peace of mind and sustainability for the longer term. With **Colostomy Association** celebrating its tenth anniversary this year, it would be wonderful to plan ahead for the next decade and beyond!

This guaranteed income would also help us to continue to :

- ❖ **PROVIDE A 24 HOUR FREEPHONE HELPLINE** to answer over 4,000 calls 365 days a year
- ❖ **VOICE YOUR CONCERNS** with the NHS and Government
- ❖ **DESPATCH PATIENT PACKS** to over 1,200 pre and post op concerned people
- ❖ **ATTEND OPEN DAYS AND CONFERENCES** Over 200 attended by volunteers

❖ **DESPATCH NURSES' PACKS**

Containing almost 14,000 unique items of patient support literature

The purpose of this article is to seek out your views, particularly as **only 25%** of our supporters have paid a donation of any kind.

Increasing the percentage of people who give regular standing order donations would be an alternative solution to our dilemma!

Trevor Andrews
Trustee

So, please tell us what you think

- **Do you think an annual fee is a good idea?**
- **What would you be willing to pay for a guaranteed copy of *Tidings* and other benefits we may be able to set up?**
- **Do you have an alternative idea?**

If you have access to the internet please complete our short three question online survey at the following SurveyMonkey link:

www.surveymonkey.com/s/G2X89MY

If not or if you prefer, then drop us a line answering the same questions, which are:

1. Would you be willing to pay an annual fee for *Tidings*?

Yes No

2. What would be your preferred annual fee?

£50 £25

£20 £15

3. What other ideas would you support or suggest?

Please return this form to: **Colostomy Association, Enterprise House, 95 London Street, Reading, Berkshire RG1 4QA**

Please ensure your form reaches the office by the end of January, 2015 to be counted.

Marketplace

advertise your events • messages • services here

If you have a product to sell, an event to advertise or a message to communicate, you can place a small advert for as little as £20. Stoma care nurses, if you would like to promote your Stoma Care Department, its services and events for FREE, then just get in touch; Contact – editor@colostomyassociation.org.uk

POUCH COVERS

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Ursula Naish designs and produces pouch covers and waterproof mattress and wheelchair covers.

As Secretary of the UA Kent Branch she offers this service to raise funds for her local group.



For further information please Contact –
Ursula Naish, 9 Oast Meadow, Willesborough, Ashford, Kent TN24 0AS
 Tel: 01233 640 863 Email: ursulanaish620@btinternet.com



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Stoma Care Information Group

Churchdown Community Association,
 Parton Road, Churchdown, GL3 2JH
 Feb 13th 2015

Cheltenham General: 0300 422 4363 or
 Gloucestershire Royal: 0300 422 6702

Oxford University Hospitals NHS Trust Stoma Care Open Day

Level 3, Academic Street,
 John Radcliffe Hospital
 Apr 25th 2015 – 10:00am–1:30pm
 Jo Buxton: Jo.Buxton@ouh.nhs.uk

Yeovil District Hospital

Carling & Wessex Suites, Westland
 Conference & Leisure Complex, Yeovil,
 BA20 2DD
 Apr 30th 2015 – 11:00am–2:00pm
 Corrina Corner: 01935 384 367

HeSRU (Consultants, Trainees and Healthcare professionals only)

Problem Stoma Course
 Exeter Castle, Castle St., Exeter, EX4 3PU
 May 12th 2015 – 8:30am–5:00pm
 Jessica Semmens: 01392 408 944



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Regular donation

Your on going commitment means CA can plan its services with confidence safe in the knowledge that regular donations will be received. Help CA to reach out to more colostomates their families and carers to give support, reassurance and practical advice to those in need. With your help we really can and do make a difference - thank you!

Please fill in this form to make a **Regular donation by Banker's Standing Order**. Check your details are correct then return the completed form by post to: **Colostomy Association, Enterprise House, 95 London Street, Reading, Berks RG1 4QA. Telephone: 0118 939 1537 if you have any queries.**

Note: Please ensure that we have your correct contact details: full name, address and postal code telephone number thank you

My Details: Title: _____ Name: _____ Surname: _____
 Address: _____
 Postcode: _____
 Telephone (home): _____ Mobile: _____
 Email: _____

Regular donation: I wish to make a **regular contribution by Banker's Standing Order** to the **Colostomy Association** in support of the charity and its on going work. I have completed the **Banker's Standing Order Form below** (Please tick).

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

To the Manager: (Bank or Building Society)

Bank Address: _____ Postcode: _____

Name(s) of Account holder(s): _____

Account number: _____ Sort code: _____

I would like to make a **regular donation*** of £15 £20 £25 £50 or other amount (please state) £

monthly quarterly annually starting on the 1st 15th 25th of month: _____ year: _____

thereafter until further notice. *Please state your donation amount in words:

(Please cancel any previous standing order in favour of this beneficiary).

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

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

Name: (IN CAPITALS) _____

Signature: _____ **Date:** / / 2015

giftaid it **Thanks to the gift aid scheme** - we can reclaim money on your donation from the government. **For every pound you give us, we can claim an extra 25p.** For example, a donation of **£15 becomes £18.75 with gift aid**, at no extra cost to you.

Thank you for your gift

I would like the tax to be reclaimed on this donation and any eligible donations that I have made in the last four years or will make to the Colostomy Association until further notice. I confirm that I pay an amount of Income Tax and/or Capital Gains Tax at least equal to the tax, not including Council tax and VAT, that the Colostomy Association and other charities and CASCs reclaim on my donations in the appropriate year (currently 25p for every £1 donated).

Signature: _____ **Date:** / / 2015

Optional Information: Date of Birth: _____ Stoma Type: Colostomy
 Reason for your stoma: _____ (Please tick) Ileostomy
 Year of operation: _____ Urostomy

(NB: The optional information is not mandatory but will help the CA learn more about you - it will not be passed on to third parties)

To donate via standing order...Please fill in the form, check your details are correct, then return this page to the Colostomy Association - thank you





Single donation

Thank you for your support

Your single donation/gift makes a HUGE difference to the work of the charity – CA can reach out to more colostomates their families and their carers with support, reassurance and practical advice. With your help we really can change lives - thank you.

Please fill in this form to make a **Single donation**. Check your details are correct, then return the completed form by post to: **Colostomy Association, Enterprise House, 95 London Street, Reading, Berks RG1 4QA. Telephone: 0118 939 1537 if you have any queries.**

Note: Please ensure that we have your correct contact details: full name, address, postal code and telephone number. Thank you.	My Details: Title: _____	Name: _____	Surname: _____
	Address: _____		
			Postcode: _____
	Telephone (home): _____		Mobile: _____
	Email: _____		
Optional Information: Date of Birth: _____		Stoma Type: Colostomy <input type="checkbox"/>	
Reason for your stoma: _____		(Please tick) Ileostomy <input type="checkbox"/>	
Year of operation: _____		Urostomy <input type="checkbox"/>	

(NB: The optional information is not mandatory but will help the CA learn more about you – it will not be passed on to third parties)

Single donation: I wish to make a **single donation** to the **Colostomy Association** in support of the charity and its ongoing work. I have completed the **Form below** (Please tick),

Single donation/gift: a donation of £15 (or more) will help cover the cost of all our patient services

(Please tick.) **Yes** I would like to make a **single donation/gift** of £15 £20 £25 £50 or other amount (please state) £ _____ to the **Colostomy Association**

I enclose my **cheque/postal order form** made **payable** to the **C.A. Ltd** and attach the completed Donation Form in its entirety.

Yes, I require a receipt (Please tick).

Single donations from individuals, groups and fundraising events are very welcome and greatly appreciated. So please keep them coming, no matter how small. Just £15.00 (or more) will help cover the cost of all our patient services.

Thank you for supporting CA – with your help – we can change lives!

giftaid it

Thank you for your gift

Thanks to the gift aid scheme - we can reclaim money on your donation from the government. **For every pound you give us, we can claim an extra 25p.** For example, a donation of £15 becomes £18.75 with gift aid, at no extra cost to you.

I would like the tax to be reclaimed on this donation and any eligible donations that I have made in the last four years or will make to the Colostomy Association until further notice. I confirm that I pay an amount of Income Tax and/or Capital Gains Tax at least equal to the tax, not including Council tax and VAT, that the Colostomy Association and other charities and CASCs reclaim on my donations in the appropriate year (currently 25p for every £1 donated).

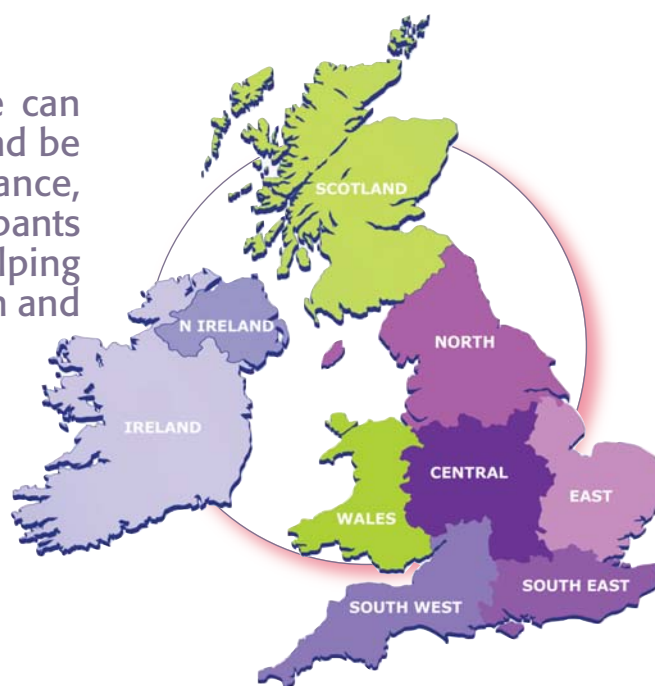
Signature: _____

Date: / / 2015

To make a single donation...Please fill in the form, check your details are correct, then return this page to the Colostomy Association - thank you



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.



“Let’s share our support group ideas”

Jackie Dudley’s article about support groups in the previous edition of *Tidings* got me thinking what a good idea it would be to share our ideas. There must be lots of good support groups out there, but let me tell you about Stevenage Ostomistics.

I had wanted to set up a support group for a long time but when I mentioned it to one of the stoma care nurses in our Trust she said: “What do you want to do that for?” I’ve no idea why she said that but I got the impression she was not keen on the idea. Eventually I gave up – too easily I hasten to add.

But during a **Colostomy Association** volunteers’ weekend away in Huntingdon in April 2011 I met Alfred Levy and he too

wanted to form a support group and was so determined to do it, he succeeded, despite also meeting with some resistance.

He attended a *Nuts & Bolts* seminar on how to set up a support group, led by Helen Bracey from Ostomy Lifestyle. Alfred also received advice from the **Colostomy Association** head office and support from the late Heather Connor who formed a successful group in Peterborough.

In October 2011, he organised a meeting in Stevenage and over 60 people attended. His objective was to find out if they wanted a support group and the majority said they did. He got a feel on that day about the kind of things people would like to do.

They didn’t want to meet and talk about

their operations, they wanted to be a social group and where necessary give support to each other and new members. **Stevenage Ostomistics** took off from there and we’ve never looked back.

Alfred found some very good premises for our meetings. It had kitchen facilities, was spacious and had ample free parking. We asked for volunteers to form a committee and started with monthly meetings in each other’s homes.

We were lucky to start with, to have Alfred as chairman and treasurer and we had a secretary to take the minutes. We kept the meetings quite informal but structured. Two of our committee members are spouses of people with a stoma. It was agreed that our

CONTINUED ON PAGE 64, COLUMN 1



AROUND THE COUNTIES REACHING OUT TO GIVE SUPPORT

CONTINUED FROM PAGE 63, COLUMN 3

support group should meet on the last Saturday morning of each month from 10.30am to 12.30pm.

We needed funds and two local councillors donated £250 to get us started. We invited manufacturers and suppliers to attend our support group meetings and make a voluntary donation. One representative attends each month with their stand.

We did not want to charge a membership fee, so we have a raffle; all the prizes are donated. Refreshments are served free of charge but we have donation boxes and people are quite generous. They also sometimes bring along some homemade cakes. This plus the donation from the reps cover our costs each month. One of our members makes greetings cards and sells them and donates the profits to the group.

So, what do we do after we've all had refreshments and a chat with all our newly found friends?

We have had a variety of speakers, sometimes humorous and always interesting and enjoyable. These have included:

- Sheila Parker, a former Tiller and Vernon girl, who gave three talks about her journey in the entertainment world;
- Zena Skinner, who amused us with tales about her first attempt at facing the camera on black and white television in the 1950s, and then on another occasion about joining the Wrens;
- a retired barrister who spoke about "Growing old disgracefully";
- Richard Whitmore, who lives locally, talked about his job as a BBC television newsreader; and
- other subjects included Astronomy, Bee keeping, The History of Hitchin British Schools, The role of Head Gardener at

Woburn Abbey, Reminiscences, Laughter is the best medicine and The Rotary Club.

The list goes on. All these people charged a fee but our funds covered it.

We also sometimes have talks about stomas. Helen Bracey from Ostomy Lifestyle came along with three very good workshops on diet, travel and anatomy, all funded by the National Lottery.

There is always a stand with literature from the **Colostomy Association**, Ileostomy Association and Urostomy Association available for people to take away. One of our stoma care nurses attends almost every time and also refers patients to us. How good is that?

Our enjoyment doesn't end there. From May to September some of us meet once a month at a local pub at about 6pm, order food for later and then play petanque. We have so much fun. Greyhound racing appealed to some, so one evening off we went to Harlow, enjoyed a basket meal and a drink. Some of us came away with money in our pockets, some broke even, and the rest...well we did warn them!

There is a wonderful theatre in Stevenage and we went to see a stage production of the *Sound of Music* followed by an Austrian meal in their restaurant. We've also enjoyed some amazing days out: a trip to a brewery (what can I say!); three outings to see television programmes recorded and one of those was *Loose Women* (it gets worse doesn't it!); we've seen two wonderful shows at Brick Lane Music Hall in London; a St Patricks Day show; and an Adult Panto (Oh yes we did!)

Two other memorable events each year have been a BBQ hosted by Alfred and his wife Sue in their lovely garden and our Christmas lunch at a local Toby carvery restaurant.

Three different manufacturers invited us to spend the day with them and were wonderful hosts, telling us the history of the

company followed by a tour and providing a lovely lunch.

We have held our own Open Day for the last three years and have had about 14 or 15 stoma company stands at each event. These events help to raise awareness and give people the opportunity to talk to reps about their products. They also help to boost our funds. That is our only fundraising event.

I mentioned our committee meetings earlier and we now hold them less frequently. We decided we should hold an AGM and have them at the beginning of one of our Saturday meetings. We keep it very brief and re-elect our committee and of course new committee members. Alfred is still our chairman but we elected a treasurer.

All the activities and events mentioned are organised by the committee members, including the refreshments and selling the raffle tickets and I have to say it works very well.

Our posters are in GP surgeries, clinics, supermarkets and anywhere people will let us display them. We now have over 100 members and have between 45 and 50 people at each of our Saturday morning meetings. Our secretary emails or sends a letter to every member once a month advising them of our next speaker, manufacturer or supplier attending and any planned events.

We hold 10 monthly support group meetings a year, one Open Day and one Christmas lunch. We have found this works very well for us and have all made so many new friends. We also produce our own annual Newsletter.

There's no right way and no wrong way, to run a support group. It's up to you, and what your members want.

Oh I nearly forgot, Alfred Levy was presented with a *Pride of Stevenage* award from the Mayor last year for his work with Ostomistics

Judy Colston



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 county

England

B

Bedfordshire

Saturday Social Club
Karen Richards: 0123 479 2278

Berkshire

E.B.O.C (East Berkshire Ostomy Club)
Jackie Dudley: 0134 442 6652
W.B.O.C (West Berkshire Ostomy Club)
Jackie Dudley: 0134 442 6652

Bristol

Bristol Ostomy Self Support (BOSS)
Janet: 01934 248 114 or
Rob: 0117 966 8021

Buckinghamshire

Milton Keynes Stoma Association
Joanne Dickson: 0190 831 8262

C

Cambridgeshire

Connections Cancer & Colostomy
Group
Bev or Sue Scott: 0135 386 0356/
0776 695 8811 or
Barbara Hunt: 0135 386 2133
Ostomistics
Alan Wright: 0135 465 3290 /
0783 666 1102

Cheshire

Stoma Support Group
Catherine McIntosh:
Crewe 01270 666 985
Stockport Support Group
Angela Simpson: 0161 320 9400 /
0800 652 6667
Warrington Ostomy Support Group
Jane Shaw: 0192 566 2103

Cleveland

Ops Group
Julie Morrisroe/Carol Younger:
0128 728 4113

Co. Durham

Bishop Auckland Stoma Care Group
Betty: 0138 881 4535

Cornwall

Carnon Downs Ostomy Support Group
Ken Jones: 0187 286 3106 or
www.cornwallostomysupport.org.uk
Cornwall Bowel Cancer Support Group
Peter Yorke: 01726 821 280 or email
quillpusha@gmail.com or website
www.cornwall-bowel-cancer-support-
gro
Ostomist and Carers Support Group
Christine Davey: 0120 883 1471
Optimists
Sue Hatton: 0132 634 0058

Cumbria

Grange Cancer Support Drop in
Marie: 0153 953 3279

D

Derbyshire

Diverted Local Stoma Support Group
Diane Manning: 0128 354 1311

Devon

Mid Devon Ostomy Support Group
Janice: 0136 377 6417 or
janicedianeparkyn@yahoo.com

Dorset

Colostomy, Urostomy, Pouch &
Ileostomy of Dorset - CUPID (West
Dorset)
Colin Clare: 0130 585 3238
Colostomy Urostomy Pouch Ileostomy
of Dorset (CUPID)
Jenny Pipe: 0120 274 0440
Colostomy Urostomy Pouch Ileostomy
of Dorset (CUPID)
Beryl Andrews: 0120 248 3303

E

East Midlands

Newhall Stoma Support Group
Diana Manning: 0128 354 1311 or
Helena: 0793 233 1850

Essex

Connect
Lin Hart: 0127 950 5273

STEPS

Jackie: 0126 845 1937

Optimistic Ostomates

Carol Booth: 0170 238 5510 or
Angela Taylor: 0170 238 5509

Redbridge Ostomists Club

Stoma Nurses - Chris/Lisa:
020 8970 8321

N.E.S.S (North Essex Stoma Support)

Secretary:
Brian Waller: 0120 654 0449

Mid Essex Stoma Support Group

Paul Foulger: 0124 522 4374,
Jeanette Johnson: 0137 651 1862

G

Gloucestershire

Vale Stoma Support Group
jfn.dursley@gmail.com or text 0794
182 7393

Ladies Big Op Group

Gill Hopkins: 0300 422 4363.
Please Note: For ladies with one or
two permanent stomas

H

Hampshire

Solent Ostomates Support Group
(New Forest Branch)

Carole Summer: 0752 770 7069

Solent Ostomates Support Group
(S.O.S.)

Carole Summer: 0752 770 7069

Wessex Urology Support Group

Adrian Kuczynski: 07910 786 978

Hertfordshire

Stevenage Ostomistics

Judy Colston: 0143 835 4018 /
neilcolston@btinternet.com or Alfred:
0176 731 6958

Hertford Stoma Support Group

Ralda: 0199 253 5311

Colonise

Anastasia: 0172 776 0981

I

Isle of Man

Stoma Support Group

Carole Cringle stoma nurse:
0162 465 0212

Isle of Wight

Semi-Colon Club

Tony Crowson: 0198 355 9326 or
CNS Helen Fulford: 0198 353 4180

Optimistics

CNS's Andie Coates & Amanda
Broadbridge: 0198 353 4009

K

Kent

M.O.G.S (Medway Ostomy Group Support)
Helen Or Tracey: 0777 360 5534

Dover Stoma Friends Group Support
Julie Bell: 0777 134 5703 or
Ros Marshall: 0130 482 2696 or
June Golding (Organiser):
0130 482 2696

Thanet Stoma Buddies Support Group
Phil (Secretary): 0184 358 7769

Atoms Support Group
Maria Culleton, SCN: 0122 776 9679
or 0782 799 7424

Royal Tunbridge Bowel Cancer Support Group
Bronwen Tetley CNS:
0189 252 6111 x 2287

Maidstone Stoma Support Group
Judy/Kirsty: 0162 222 4305

Ashford Stoma Support Group
Ron Huckstep: 0794 131 0681 or
Margaret Webb: 0123 362 8807

L

Lancashire

North Manchester and Bury Stoma Support Group
Julie Meadows (SCN): 0161 720 2815
or 0784 120 6910

Tameside Ostomisticles
Paul Seavers: 0777 135 9046

Oldham Stoma Support
June Wilde: 0161 312 5538

Trafford Bowel Care
Jackie Carey Secretary: 0161 748 9659,
Doreen: 0161 962 7818,
John: 0161 748 4655

Leicestershire

Kirby Ostomy Support Group.
Colostomy, Ileostomy and Urostomy in Leicestershire
Janet Cooper: 0116 239 2844
kosg2013@btinternet.com

Lincolnshire

Sutton Bridge and Long Sutton Ostomy Group
0140 635 1617

March Group
Sharon Palmer: 0741 482 8867 or
sharonpalmer44sp@gmail.com

Grantham Support Group
Bobbie/Amanda: 0147 646 4822 or
grantham.colorectal@ulh.nhs

Friends East Coast Support Group
Betty: 0120 572 4120,
Sheila: 0120 536 4493

London

ESsence (Ealing Stoma Support Group)
Wendy Hetherington: 0771 733 5884

St. Thomas' Hospital
CNS: 0207 188 5918

Surrey & South London Bowel Cancer Support Group
Sue Berry: 0173 755 3134 or
John Amos: 020 8668 0796

Bowel Cancer Newham
Scyana: 020 8553 5366
scyana@tiscali.co.uk

Homerton Hospital Bowel & Stoma Support Group
Angela Davy: 020 8510 5318 or
020 8510 7599

South Woodford Support Group
Nurse Christina & Lisa: 020 8535 6563

M

Merseyside

I.C.U.P.S
SCN: 0151 604 7399

Middlesex

Semi-Colon Club
Pat Black or Kathryn Foskett:
0189 527 9391

Inside Out
Sarah Varma: 020 8235 4110
Bob (chairman): 020 8428 4242

N

Newcastle

NHS Molineaux Walk In Centre
Lesley Brown: 0191 282 6308

Royal Victoria Infirmary Support Group
Gordon Weatherburn: 0191 234 1109

Norfolk

Stars
Anne Browne: 0160 366 1751

Kings Lynn Ostomy Friendship Support Group
For more info please call:
0155 369 1370 / 768271 / 775698

Northumberland

Hexham Ostomy Group
Judith: 07967 927 286

Berwick Ostomy Support Group
Bobbie Minshull: 07714 479 320

Northumberland Cancer Support
members@northumberlandcancersup
portgroup.co.uk

Nottingham Colostomy, Ileostomy & Urostomy support group
Rosemary Brierley: 0115 982 6691

Nottingham Stoma Support
Jenny or Kate: 0115 962 7736/
Mrs B Heath: 0115 966 3073

North Notts Stoma Support Group
Tore and Nicky Norman:
0177 371 5460

O

Oxfordshire

Oxfordshire Ostomy Fellowship
Pat Longworth: 0123 552 4163

S

Shropshire

B.O.T.S. (Bums on Tums)
Irene Constable: 0169 123 8357

Somerset

Devon IA
Martin Hornby: 01458 251 095 or
email: devon@iasupport.org

Staffordshire

Outlook
Moirra Hammond: 0178 262 7551

Suffolk

West Suffolk & District Stoma Group
Jessica Pitt stoma nurse:
0163 851 5525

East Suffolk Ostomy Group
Marion Fisher: 0147 331 1204

James Pagett Ostomy Support Group
Sandra Hutchings: 0150 258 5955

Surrey

Epsom and District Stoma Support Group
Lindsay, Trevor or Sheena:
0137 273 5925

Sussex

Chichester Stoma support Group
The Stoma Care Team: 0124 383 1527

The Ostomy Friends Group
Jane Quigley: 0132 341 7400 ext 4552

West Sussex Princess Royal Stoma Support
Tina Walker: 0144 444 1881 ext 8318

Brighton & District Support after Stomas (SAS)
Sylvia Bottomley: 0127 355 4407

T

Teeside

Dales & Vale Ostomy Support Group
Carol Watson: 0167 798 8150 /
pcw-agw@tiscali.co.uk or Mr Simpson:
0167 742 4877 / 0754 625 9132 /
rolandsimpson1945@gmail

Tyne & Wear

Gateshead Stoma Patient and Carer Support Group
Stoma Care Nurses: 0191 445 3152 or
email stuart.sutcliffe81@yahoo.com

W**West Midlands**

Coventry Stoma Support
Martin: 0794 738 5643

Wiltshire

Swindon IA
www.swindon-ia.org.uk
Wessex Stoma Support Group
Michael Slater: 0172 274 1233 or
wessex.stoma@yahoo.co.uk

Worcestershire

Kidderminster & District Collossus
Support Group
Brendon Drew: 0129 940 0843

Y**Yorkshire**

Acorn Ostomy Support Group
Michelle: 07580 693 155 (After
6:00pm)
Barnsley Bottoms Up Stoma Support
Group
Stoma Nurses: 0122 643 2528 or
Celia Utley (Chairman):
0122 628 4262
Leeds Bowel Cancer Support Group
Lynda Castle (Colorectal Nurse
Specialist): 0113 206 5535
Behind You (Calderdale &
Huddersfield Bowel Cancer Support
Group)
Stoma Care Nurses: 0148 435 5062
The Hull and East Riding Colostomy
Support Group
Pete Smith: 07989 565 335 or
Pete Rennard: 07939 518 642 /
0148 279 3966 or Rosanna Grimsby:
0148 280 1575. Website:
www.hercosg.org.uk
Rotherham Ostomates Caring Support
Karen Kilford: 0788 057 5758
Scarborough Stoma Support Group
Sister Jean Campbell: 0172 334 2388,
Amanda Rowe: 0172 334 2446
Dewsbury & District Ostomy
Janet/Eileen: 0844 811 8110
Airedale Stoma Support
Sue Hall: 0153 521 0483

Northern Ireland**Co. Antrim**

Royal Victoria Hospital - Belfast
Sarah Haughey/Audrey Steele:
028 9024 0503 Ext 3483
Colostomy Association Volunteers
Northern Ireland
Chris Wright: 0772 071 7771
Mater Hospital
Karen Boyd - Stoma Nurse:
028 9074 1211 Ext 2329

Co. Armagh

Daisy Hill Hospital Support Group
Bernie Trainor:
028 3083 5000 Ext 2222
Craigavon Area Hospital
Mary Jo/Bernie: 028 3861 2721

Co. Down

Ulster Hospital
Hazel/Martina: 028 9055 0498
North Down Stoma Support Group
Adrian Ewing on 07850 741 511

Londonderry

Causeway Support Group
Mary Kane: 028 7034 6264

Scotland**Ayrshire**

Stoma Care And Recovery (SCAR)
Maggie: 0129 427 1060/ 0781 773
6147 maggie13@sky.com or Rhona:
0129 455 7478
Ayrshire & Arran Stoma Support Group
Jim Krasewitz: 0129 222 0945

Fife

Fife Ostomy Support Group
Ishbel Barr: 0159 277 2200

Lanarkshire

G66 Support Group
Les Ireland 0141 776 3866
Glasgow Stoma Support group
Chairperson: Maureen O'Donnell:
0123 643 6479

Midlothian

GOSH (West Lothian)
Scott Pattison: 0750 216 3644

Scottish Borders

Stoma Support Group
Nancy Fraser: nancyfraser@talktalk.net
or 0145 037 4012. Fiona Gentleman:
r.gentleman@sky.com or
0145 037 1063

Wales**Bridgend**

Bridgend Ostomy Patients Support
Group
Anita Brankley (Secretary)
0165 664 5602 or
Pat Jones: 0165 678 6103

Gwent

Blaenau Gwent Self Help
Celia McKelvie: 0187 385 2672
After 6pm

Mid Glamorgan

C.A.S.S Colorectal and Stoma Support
Group
Colorectal Nurse Team:
0168 572 8205

Monmouthshire

Cwmbran Ostomy Support Group
(COSG)
Pippa Lewis: 0163 379 1339 /
07504 713 069

Rhondda Cynon Taf

Royal Glamorgan Stoma Care Support
Group
Domenica Lear: 0144 344 3053

Swansea

Swansea Ostomy Self Help Group
Glynis Jenkins: 0179 241 8245

Channel Islands**Guernsey**

Guernsey Ostomates
Luci Deane 0148 123 6077 /
lucideane58@gmail.com

Republic of Ireland**Co. Mayo**

Mayo Stoma Support
Marion Martyn: 094 902 1733

Dublin

Bowel Cancer Support Group (ICS)
National Cancer Helpline:
+353 1 800 200 700 or
Olwyn Ryan: +353 1 231 0500

France**Provence**

Stoma France
Adrian March: +33 494 501 136 or
email: info@stoma.fr

Spain**Alicante**

Costa Brava
http://www.ostomyinspain.org/

10th Anniversary Open Day 2015 & Fashion Show

Royal Berkshire Conference Centre | Madejski Stadium | Reading



Booking Form



I would like to attend the following **Colostomy Association** events (please insert the number of places required).

Quantity

Open Day on Saturday 11th July 2015 *free of charge*

Fundraising Gala Dinner on Saturday 11th July 2015 *£45 per person*

Fashion Show on Sunday 12th July 2015 *free of charge*

I enclose a cheque made payable to CA Ltd totalling

£ .

PLACES ARE LIMITED SO PLEASE BOOK EARLY TO AVOID DISAPPOINTMENT

Details: Title:	Name:	Surname:
Address:		
		Postcode:
Telephone (home):	Mobile:	
Email:		
Stoma Information: Year of Birth:	Stoma Type:	Colostomy <input type="checkbox"/>
Year of operation:	(Please tick)	Ileostomy <input type="checkbox"/>
Reason for your stoma:		Urostomy <input type="checkbox"/>

(This information will help the Colostomy Association learn more about you and how we can help – it will not be passed on to third parties)

Please return this form to: **Colostomy Association, Enterprise House, 95 London Street, Reading, RG1 4QA** by **11 June 2015**

Tickets for the fundraising Gala Dinner will be sent to you later in the Spring.

Look out for more information about our 2015 celebrations in the coming months!





10th Anniversary Update

2015 will be a very special year for the Colostomy Association which will be celebrating its 10th Anniversary. Come and join us this July to celebrate our successes of the past ten years and our plans for the future.

Open Day

On Saturday 11th July our Open Day will run from 9:30am to 4:00pm, with over 20 exhibitors, prize draws, a range of topical talks including a session on hernias, stoma care nurse appointments and free refreshments (donations welcomed). This is also your opportunity to meet the staff, local volunteers, Trustees and our President, Mr Ian Daniels FRCS.

Fundraising Gala Dinner

That evening, our special Gala Dinner will include a three course meal from 7:00pm, an awards ceremony, fun photo booth and cabaret style entertainment. This is a 'jacket and tie' event and tickets are priced at £45.00 per person. Some of the evening's celebrations are being sponsored by companies like Dansac, Ostomart, Salts Healthcare, CliniMed, Securicare and Trio Healthcare (so far). Do invite your family and friends to this special celebratory evening and make it a night to remember.

Fashion Show

On the Sunday morning at 10:00am our fashion show will open its doors with refreshments and a fun fundraising

handbag swap activity. There will also be time to visit the exhibitors' stands, followed by the fashion show from 11:00am - closing just before lunch time. Colostomates of all ages will be modelling a range of clothes on the catwalk and the University of Buckingham will be selling their range of eco-shade sunglasses. Our fashion show and the image consultant are being sponsored by ConvaTec, which is greatly appreciated.

There has been a good response to our previous request for models for the fashion show and all the places have now been filled. It was wonderful to receive so many enquiries! Our image consultant will be calling each person in the Spring to chat through what's involved and we're looking forward to meeting everyone in person later in the year. It promises to be an entertaining event so book now!

'As-New' Handbags Wanted

Please dig out any good quality handbags you no longer use and keep them on one side for the handbag swap activity on the Sunday morning. It should be fun! We're hoping to raise extra funds through this unusual activity – not to mention publicity in the local papers!

The donated bags will be available for £10.00 each.

Bring your bags in when you come down, or, if you're not able to attend, but have some attractive "as new" handbags that

might be suitable for the stall, please post them to the office. Many thanks.

Hotel Accommodation

If overnight accommodation is required that weekend, a hotel is on site at the Madejski Millennium Hotel, Reading Football Club Stadium Complex. Reduced rates are offered for Friday 10th July 2015 and Saturday 11th July 2015. Double room, with single occupancy including B&B at £72.00 including VAT or double room, with double occupancy including B&B at £84.00 including VAT. To book, please contact the Hotel Reservations Team direct on **0118 925 3500** and quote "**Col 110715**" to obtain the discounted prices. (Note: cancellation of room/s must be made before 2:00pm on the day of your stay.)

Do join us!

We'd be delighted if you could join us at the Royal Berkshire Conference Centre in Reading on 11th–12th July so why not make a weekend of it? Please complete the booking form and send it in early to avoid disappointment. Hope to see you there!

Cancellations

If you are unable to attend after booking, please let us know as soon as possible, so that your place(s) can be reallocated as numbers are limited and we expect these events to be popular.

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* Coloplast clinical study 2010

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