colostomy association

Tidings

Autumn 2008 Issue 11

Dedicated to Colostomates and their Carers

inside...

Full Conference Coverage

plus...all our regular features

Stoma Care Professional writes about...body image


Tack & Adhesion
Flexibility
Absorption
Erosion Resistance
Ease of Removal

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FROM THE EDITOR

Tidings
Magazine

Dear Readers...

I would like to take this opportunity to thank the Trustees for appointing me as the new editor of 'Tidings' magazine and to introduce myself to you all.

I consider this appointment to be a real privilege, and I will do my utmost to continue the great work established by the previous editorial team, especially past editor Rosemary Brierley.

Some of you may be aware that I have worked for the CA for sometime now and also previously for the BCA. I first became involved with 'Tidings' Magazine when I was approached by Celia Waters to assess the design and production of 'Tidings' which was then a much smaller publication. Like Celia, I could see that 'Tidings' was of real benefit to it's readers, indeed as Virginia Ironside mentioned during her talk at the CA Conference 'it's like having a chat with a friend'. That sentiment is exactly what I want 'Tidings' to continue to be, a friend.

I would like to urge you all to get more involved with 'Tidings' this is your magazine - let's make it a publication that truly represents all colostomates and all aspects of 'living with a colostomy.' I want 'Tidings' to be your voice, to share your concerns, reflect your daily lives and deliver even more quality information, so much so that, if anyone picks up 'Tidings' they gain real insight into the world of the colostomate.

Although, I am not a colostomate myself, my mother became a colostomate late on in her life. Our journey together has made me a passionate champion for those who are 'living with a colostomy'.

I will endeavour with your help to improve the standing of 'Tidings' - so that it becomes the leading magazine within it's field and is recognised as such.

Jane

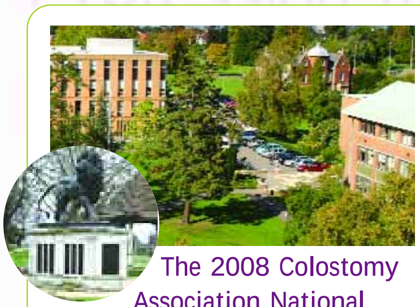
Jane Wood EDITOR

Contact the editor:
cass@colostomyassociation.org.uk

"Building on Success"

Colostomy Association National Conference 2008

Over three hundred ostomates, relatives and friends - health care professionals, Patient Association representatives and seventeen manufacturers, distributors and suppliers attended the second CA National Conference held on the 11th September 2008 at the Palmer Building, University of Reading...



Courtesy of Reading University

The 2008 Colostomy Association National Conference began on a rainy September morning but despite the rain it didn't dampen the spirits of all those attending.

Over three hundred ostomates, relatives and friends came together from all over the UK to attend the conference making it a 'great success'.

Others supporting the CA Conference were health care professionals and Patient Association representatives.

Over seventeen manufacturers, distributors and suppliers also attended. Their representatives manned an amazing array of colourful trade stands, which created quite a spectacle – each stand offering a myriad of stoma care products, support garments and clothing.

The venue for the Conference was the Palmer Building situated on the Whiteknights Campus of the University of Reading. Named after the Palmer family, the famous biscuit manufacturer Huntley & Palmers, Reading. Built in the 1960s, the Palmer Building, has recently been given a new state-of-the art interior. The venue suggested by Monty Taylor (Trustee) included a theatre, which was used for the presentations, and fashion shows and proved to be a perfect setting. With additional open areas for trade stands and refreshment and toilet facilities on ground level, ensuring that the Conference ran smoothly.

Ray Goddard (Office Manager, Treasurer and Trustee) who organised this year's National Conference also arranged a shuttle service for visitors, taking to and from Reading Station to the venue.

Those attending the Conference began to arrive from 9:30 am onwards and were welcomed and registered by the friendly faces of Gill, Jo and Beryl, staff from CA Head Office. The atmosphere began to build and the usual Conference hubbub could be heard. Sue Hatton (Chairman) and Ernie Hulme (Vice Chairman) were meeting and greeting people and making introductions to new and old friends, people were chatting having tea and coffee and wandering around looking at the trade stands, the day had begun!

At around 10:00am the theatre began to fill up for a welcoming address from Sue Hatton. Thanking everyone for coming Sue then acknowledged the work of all those who had made the event possible giving special thanks to Ray Goddard for pulling the event together and to the University of Reading for the use of their excellent facilities. Outlining the day's events Sue commented, "We have a wide range of presentations going on during the day from health professionals and ostomates, plus a fashion show called 'Simply the Best – Dressed'. Sue urged delegates to visit the trade stands and said, "Take time to talk to the company representatives to see what is available to you".

Sue Hatton highlighting the work of the Colostomy Association

Sue then outlined the work achieved by the Trustees and the Colostomy Association over the past year.

Sue thanked her fellow Trustees for their support and hard work. Ernie Hulme for his work with 'Tidings' and volunteers, Ray Goddard for his organisational skills and smooth running of the office and Monty Taylor for his experience and help in acquiring new premises in London Court for the Association, setting up the raffle for the car and the 500 Club.

Although Trustees, Marilyn Beynon and Robin Mills were unable to attend the Conference, Dr Adrian March a former Trustee, had flown over from Provence, France. Adrian is now a consultant to the CA. He has set up his own website for British people living in France (www.stoma.fr) He is also an expert on getting back to sporting life, especially swimming. Sue suggested delegates take advantage of his infinite wisdom and quiz him about exercise.

Thanking the girls at Head Office, Beryl Goddard, Office Helpline and Support Group Administrator, Gill Herbert, Office Administrator and Jo Mckenzie, Database Administrator, Sue said, “Many of you will have heard their voices and will now be able to put a face to the name.”

Sue told everyone that ‘Tidings’ magazine had gone from strength to strength and was now reaching a readership approaching 30,000 and that ‘Tidings’ had now increased from 40 pages to 48 pages. Thanking Rosemary Brierley (recently retired Tidings editor) for producing the last 8 editions of such a ‘brilliant magazine,’ she went on to say, “Our publicist Jane Wood has now filled her position. Although Jane is not a colostomate, she cared for and supported her Mother for four years through bowel cancer culminating in her Mother becoming a colostomate at the age of 81, so she has plenty of understanding and experience of caring”.

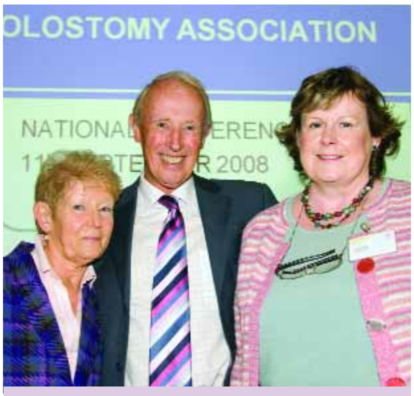
Sue also highlighted the new literature that has been produced this year – particularly Stoma Reversal and Rectal Discharge booklets plus a revised Carers leaflet and the fact that during the past twelve months CA had sent out nearly 12,000 copies of literature to stoma nurses in hospitals all over the country. She also drew attention to the CA website which has been updated and expanded to include a wealth of information along with details of support groups and open days.

“We have also held two Induction Days for thirty contact volunteers, many of whom have incredible skills which they are prepared to bring to the Colostomy Association”. Sue went on to say, “I’d like to take this opportunity to thank all our wonderful volunteers who support ostomates all over the country. You are the backbone of our Association and sometimes you leave us breathless with your enthusiasm and drive!”

As a result of the Induction Days one of the new volunteers Clive Blanchard suggested the Colostomy Association hold a ‘Strategy Meeting’. This idea was taken up and the meeting went ahead last month involving Trustees and Office staff – a ‘brainstorming’ approach was taken where all involved put forward views and suggestions for the future of CA, the day was extremely positive!

Sue concluded her presentation, “We are currently working on some very exciting plans, which will move the Colostomy Association forward. Further details will be included in a future issue of Tidings”.

Why I was determined to secure Professor Bill Heald OBE and Sister Ann Leppington-Clarke for the CA...



L-R: Ann Leppington-Clarke, Professor R J Heald OBE with Sue Hatton

I was adamant and determined to secure Professor R. J. Heald OBE (Surgical Director of the Pelican Cancer Foundation) as the President of the Colostomy Association and to invite his colleague Sister Ann Leppington-Clarke to become Liaison Stoma Nurse to the Colostomy Association. I am proud to announce that I have achieved both goals!

How did I come to know both these eminent medical professionals? In 1997, I had a tumour removed from my rectum, followed by chemo and radiotherapy, which I underwent in hospital in Germany. Unfortunately, I suffered a deep vein thrombosis (DVT) in my groin and became extremely ill. I was then sent back to the UK and referred to Professor Heald for a second opinion. After further investigation, I required another operation and a year later, Professor Heald performed a Total Mesorectal Excision (TME), which resulted in a perfect stoma.

The Stomacare/Endoscopy Sister at the Basingstoke Hospital was Ann Leppington-Clarke who worked closely with Professor Heald. Sister Ann cared for me, she was great a no-nonsense person who gave me real confidence in myself. Six weeks after the operation I returned to Basingstoke to have the stents removed. Before this procedure, Sister Ann told me that I should have a ‘nice clean bowel’ so I was frog marched to a tiny loo and taught to irrigate! I haven’t looked back and have had a ‘nice clean bowel’ nearly every day for the last ten years!

I am indebted to these two phenomenal people who are both leading lights within the Pelican Cancer Foundation. The Foundation is dedicated to the development and teaching of multi-disciplinary surgery for pelvic and liver cancers. Both Professor Bill Heald OBE and Sister Ann Leppington-Clarke will bring great wisdom and experience to the Colostomy Association, which I hope, will aid us in our work in helping to support all colostomates.

Sue

Sue Hatton
Chairman of Trustees

It was a very proud moment for Sue when she announced that Professor Bill Heald OBE, M. CHIR. FRCS, one of the most eminent Professionals in the Colorectal world and Director of Surgery at the Pelican Cancer Foundation based in Basingstoke had agreed to become the President of the Colostomy Association. Sue also introduced Sister Ann Leppington-Clarke, who has worked in colorectal care with Professor Bill Heald and the colorectal team for 27 years had agreed to become the Liaison Stoma Nurse for the Colostomy Association. Sister Ann Leppington-Clarke retired from the NHS in 2003 and presently works with the team as Colorectal Nurse specialist at The Hampshire Clinic where she counsels and teaches patients and their carers about stoma care and colorectal cancer. Both Professor Bill Heald and Sister Ann Leppington-Clarke are Trustees on the Board of the Pelican Cancer Foundation.

At this point, Professor Heald began his presentation by thanking Sue for her extremely kind introduction and warm welcome to the Colostomy Association. He said that “patient associations have more clout than doctors or surgeons”. Professor Heald then went on to give a fascinating insight into his work, explaining that his main interest for the past 20 years has been the research and development of surgery referred to as the Total Mesorectal Excision for rectal cancer or TME for short. Through his interest in camera technology, he has been able to film surgical procedures throughout the world using the latest high definition cameras

“Building on Success”

Colostomy Association National Conference 2008

Biography:

Professor Bill Heald OBE MChir FRCS
Surgical Director, Pelican Centre

Professor Bill Heald OBE providing Conference with an insight into his world

Bill Heald is Director of Surgery at the Pelican Cancer Foundation. His main interest for the past 25 years has been the research and development of the Total Mesorectal Excision (TME) technique for rectal cancer. He is a former Vice-President of the Royal College of Surgeons of England. He is past President of the Section of Coloproctology at the Royal Society of Medicine and of the Association of Coloproctology.

Honorary and Foreign Positions

- Elected Member of Council, Royal College of Surgeons of England
- Vice President, Royal College of Surgeons of England
- Personal Chair, University of Southampton
- Honorary Doctorate, University of Linkoping, Sweden
- Honorary Professor of Surgery, University of Belgrade, Yugoslavia
- Honorary Professor of Surgery, University of Leiden, Netherlands
- Honorary Fellowship of Royal Society of Medicine
- Honorary Fellowship of Association of Coloproctology of Great Britain and Ireland
- Honorary Fellowship of Royal Society of Medicine
- Honorary Member of German Surgical Society
- Honorary Member of Austrian Society for Surgery
- President, International Colon & Rectal Club
- Surgical Director TIC, Shanghai
- Chairman of Sichuan Gastroenterology Society
- Member d’honneur de l’Association Francaise de Chirurgie
- Honorary fellowship of the German Medical Society
- Centenary medal of the French Cancer Society
- Honorary fellowship of the Swedish Surgical Society
- The Israel Society of Colon and Rectal Surgery

and projectors. This allows superb clarity for the viewing audience of the intricate structures of the pelvis.

Increasing evidence in medical literature throughout the world shows colorectal cancer treatment to be the most dependent on surgical technique. There is a greater difference in outcome than in any other cancer in terms of cure, the number of permanent colostomies necessary and various other disabilities, including impaired sexual function. The technique developed by Professor Bill Heald at the North Hampshire Hospital, is now being adopted across the country by surgeons who attend interactive workshops, held at the Pelican Centre. The work carried out on colorectal cancer at Pelican is a leader in its field.

Professor Heald also drew our attention to others who were working in his field in the past, he mentioned a lady called ‘Dame Louisa Brandreth Aldrich-Blake, DBE (1865-1925)’ who was one of the first British women to enter the world of medicine. Throughout her career, Dr. Aldrich-Blake was associated with the Elizabeth Garrett Anderson Hospital, becoming the senior surgeon in 1910. During the years of the First World War, many of the male surgical staff of the Royal Free went on foreign active service and Louisa took increased responsibility for the surgery, becoming consulting surgeon to the hospital. She was the first to perform operations for cancers of the cervix and rectum. Professor Heald also mentioned William Ernest Miles 1869-1947, Miles particularly concerned himself with the surgery of the malignant diseases and affections of the colon. His surgery is known as the ‘Miles’ operation – a combined abdominoperineal resection for cancer of the lower sigmoid and rectum.

Lastly, he mentioned British surgeon, Bryan Brooke who invented the first working ileostomy. Brooke, was the driving force behind the foundation of an ileostomy association in Britain, which we know as the IA (Ileostomy Association). Brooke was one of the first surgeons to encourage his patients to form groups to meet new patients to sustain them through the emotional and physical effects of surgery. As Founder President of the Ileostomy Association from 1957 to 1982, his compassionate understanding of members’ concerns proved to be invaluable.

Professor Heald rounded up his presentation by saying that “choice, knowledge and counsel” were invaluable factors that when brought to the fore and used together could help patients face life-changing events. He also said “that patient associations have the ability to act as an interface between stoma nurses and colorectal specialists and were a force for good for the patients they represent”.

Sister Ann Leppington-Clarke

The baton was then passed by Professor Heald to Sister Ann Leppington-Clarke who with absolute precision took it up and led the audience through a life dedicated stoma care and nursing.

Sister Ann began her career as a stoma nurse at the Royal Hospital Wolverhampton and then moved to the North Hampshire Hospital where she was appointed Stoma Care Nurse specialist and Endoscopy Unit sister in 1981 and started the Colonoscopy service. She has worked in Colorectal care with Professor Heald and the colorectal team for 26 years. Sister Ann went on to describe Professor Heald as “a bit of an Evangelist!” but she added “he is really an enthusiast and an inspiration to all and offers a different ‘can do’ approach to cancer.”

With thirty-four years in stoma care, Sister Ann Leppington-Clarke has a wealth of stoma related knowledge, which she shared with the audience. She talked about the improvements in stoma care, the new advances, wealth of appliances and improvements in patient care. She mentioned that the early stoma appliances were made of rubber and that some patient still preferred them. She also mentioned new advances such as stoma adhesives and hydrocolloid adhesives. Sister Ann touched on the development of

“Building on Success”

Colostomy Association National Conference 2008

Ostomates walk the walk for ‘Simply the Best Dressed’...

Maureen Kelly-Smith
(PR Manager - SecuriCare)

Thank you from the CA...

We would like to thank SecuriCare for their support and Maureen for her hard work organising the Fashion Show and for making it a great success.
A huge thank you also goes to...
Mr Gordon Stenton Managing Director and Ms Frances Hickman General Manager of John Lewis - Reading for supporting the event and to their wonderful Staff for giving their time and expertise.

The fashion show began with a warm welcome and introduction from Maureen Kelly-Smith (PR Manager-SecuriCare Medical). Maureen announced, “Welcome to ‘Simply the Best – Dressed’ Fashion Show!” “All the models taking part in the show are ostomates, so please give them a big round of applause as it has taken quite a bit of courage for them to do this!” “Each model will be showing two outfits and I think you’ll agree they look fantastic”. And they did!

With the music booming, Maureen gave a stunning running commentary describing each outfit in great detail - she told the audience interesting and exciting facts about each ostomate in turn, here are just a few, Vernon Simmons had been tarred and feathered during his initiation as a Master Cooper, Beryl Goddard who thought she would never be able to have children because of her medical history has two healthy sons, and Roger White had flown in a Lancaster Bomber.

All the models taking part were ostomates and some were CA volunteers - Claire Duffy, Beryl Goddard, Jackie Dudley, Roger White, Alex Holland, Monty Taylor, Janet Bradley, Sheila Howard, Vernon Simmons and Anita Basile. They really did look a picture twirling and strutting their stuff!

Roger White dressed in casuals as if on holiday came in on cue, cheekily taking pictures of the audience, which went down very well. The audience clapped to the music, the models relaxed and everyone enjoyed a splendid fashion show.

Finally, the models lined up in front of the audience to take a bow and Maureen thanked all those for taking part, particularly the models for their bravery and those who had helped make the show a great success. She especially thanked, Shelley, Sara and Caroline from John Lewis for their help and advice with the all outfits, Sandra and Yvonne for the hairdressing and Rachel and Amy from Bobbi Brown for the make up.

A CliniMed Associate Company
SecuriCare

John Lewis Reading

odour proof laminated pouches and effective filters plus the development of ‘quiet’ film, which replaced the previous film, that had been noisy and crackled, like ‘crisp’ packets!”

Improvements in patient care, Sister Ann commented were helped by a greater ‘openness’ between medical professionals and their patients and ‘ownership’ of problems was recognised by surgeon and patient alike. She was also delighted that patients these days have a greater choice of appliances and stoma care products, and that support for patients and their carers had improved and was both informed and informal.

Both Professor Heald and Sister Ann Leppington-Clarke took part in an informal Question and Answer session with members of the audience; Sue Hatton then thanked both speakers for their time after which there was a short break before the fashion show! (Opposite)

Lunch took place nearby at the Cedars restaurant just a stroll away from the Palmer building. People then began to trickle back to the Conference and many took the opportunity to visit the trade stands and talk to the representatives about the profusion of different products on offer and to pick up samples that they could take away and try at home – there was a great buzz.

Then it was time for the rest of the presentations, the afternoon session kicked off with a lively presentation from journalist and writer Virginia Ironside who gave a very honest and open-minded talk.

Virginia started by saying, “I guess I’m here to talk about the bag” she asked the audience directly “Do you talk about it?” She confided that the more she talks about the ‘bag’ the less embarrassed she feels and the more at ease she feels. She pointed out that people seemed to find it a difficult subject, one that, they can’t possibly talk about!

Virginia Ironside

She hinted that the media i.e. newspapers, had mentioned the possibility of certain figures in the public eye having a colostomy but that none had come forward and owned up to it. She said "maybe its because its all about 'Poo' and that seems to be a Taboo in our society, I don't know, it seems mad to me as Mum's and Dad's we all manage to deal with our baby's bottoms, so what's it all about!" Virginia went on to say, "Being the owner of a 'bag' I have to say, isn't the end of the world. Once covered by clothes (even tight ones), a stoma bag is virtually invisible. Of course, one's always paranoid about the smell, but there doesn't seem to be a faint whiff of anything". She also said she wished that stoma bags could be made a little more fashionable and not flesh colour!

So how did Virgina come to have a 'bag' as she likes to call it? From the age of 30, Virgina suffered with a chronic condition called Ulcerative Colitis - bleeding ulcers in the colon. She was lucky she didn't have many flare-ups and for many years was trouble-free, until recently. She explained, " I got weaker and weaker, iller and iller, and (because steroids make you manic) higher and higher, until eventually, last summer, after a month in hospital and every immuno-suppressive drug there is, the doctors said there was no other drug treatment left and, er, perhaps I'd like to consider (or "opt for") surgery. As I'd had to be on blood transfusions for two days, there wasn't really much choice".

"Before I had surgery, I remember thinking that I would rather commit suicide than ever wear a bag - that, I thought, was the ultimate, most horrible thing I could imagine. Now I know differently, I really don't see what the fuss is all about". Virgina went on to say that with the bag she has more control and doesn't have to panic about finding a loo. She admitted that she thought she would have to wear different clothes but she now realises that the bag doesn't stop her wearing what she pleases!

Virginia said she was grateful to the Colostomy Association for inviting her to speak and that she very much enjoyed reading 'Tidings' magazine, and likened reading it to having a 'chat with a friend'.

At the end of her talk, she asked the audience about their own likes and dislikes about their 'bag' and discovered that the likes outweighed the dislikes dramatically as there were none!

Sue Hatton thanked Virginia for coming to the Conference and then introduced the next speaker, Dr. Rory Smith, Principal Consultant, with Emmark Technology.

Professor Atsuko Maekawa -
a Japanese Stoma care nurse and
Professor at Nagoya University

Conference with an international appeal...

We were delighted to welcome Professor Atsuko Maekawa - a Japanese Stoma care nurse and Professor at Nagoya University to this year's CA Conference.

The Professor contacted the CA with a request to attend the Conference via email. She revealed that she and her late husband a colostomate had visited the Colostomy Welfare Group in 1983.

Professor Atsuko Maekawa had also studied with Dr. Kingsley Simmons at Hertfordshire University-Faculty of Health and Human Sciences with special interest in Ostomy Adjustment.

Whilst at the National Conference, the Professor mentioned the Japanese Ostomy Association, Inc. (JOA) a volunteer-based incorporated organisation dedicated to provide education, information and support for people who have or will have intestinal or urinary diversions.

The Professor hoped that the CA and the JOA could forge links as she said "Your voice is important and as are these issues".

Japanese Ostomy Association, Inc.
Website: www.joa-net.org

Rory took the audience through the in's and out's of recycling. He gave an overview on energy and talked about what types of raw materials go in to the manufacture of products and how this affects the worlds resources. Manufacturers were now so much more aware and were really trying to use less materials.

Rory went on to mention that it is not illegal to place used ostomy bags into general household waste and that there are clinical waste collections services run by local authorities around the country, but the service was patchy. He discussed how well Britain was doing with recycling and went into great detail about the different groups of plastics and how to recognise the various recycling symbols usually found on the base of many plastic containers. At the end of the presentation Sue Hatton asked if there were any questions and held up a leaflet that a member of the audience had passed on to her. It had been produced by a local authority about recycling, Sue said "It would be good if CA could do something similar. It is definitely something CA should address".

The last presentation was from Janette Berry – Clinical Nursing Specialist at Epsom General Hospital. Janette talked about her previous involvement with the British Colostomy Association. She said, "As a result of a number of very confused telephone calls to the BCA helpline about disposal of pouches and bags, the BCA decided to commission a survey to find out what ostomates knew about disposal". The survey was inserted into Tidings and readers were asked a number of poignant questions relevant to their experiences. The feedback was then analysed and various conclusions were noted.

One of the findings seemed to suggest that a small proportion of those surveyed couldn't remember what the stoma nurse in hospital had advised about disposal of pouches and bags. This led Janette on to talking about the fact that when people are in hospital and are poorly they are not thinking about issues that may affect them when they come home. She said that "A leaflet about disposal would be good and should be included in the patients discharge pack," also commenting "Local authorities needed to be better informed about the disposal needs of ostomates".

Sue thanked Rory and Janette for their presentations and then went on to introduce the final event, which was a repeat of the earlier fashion show.

Summing up the days events Sue thanked everyone once more for attending the Conference, giving special mention to all those who had given their time especially all the speakers for their informative and lively presentations and all those involved with the spectacular fashion show. Finishing up by wishing everyone a safe journey home Sue looked forward to having even more news to pass on at next years Conference.

CA’s First Induction Day for Volunteers...

The new offices of the Colostomy Association at London Court, were well and truly baptised by two induction day meetings for new volunteers held on 11th and 17th July. Twenty-one new volunteers bravely coped with the Reading traffic, parking, taxis and, as is usual this year, grim weather, to attend the CA’s first Induction Days.

L-R Peter Massey, Sheila Ticehurst, Gill Herbert, Tom Reid, Sue Hatton, Peter Martin, Elaine Payne, Clive Blanchard, Mary Martin and Bob Buckley

Some of the Trustees remembered when we enthusiastically decided that it was pay back time after we had our colostomies. In Ernie Hulme’s and my case it was eleven years ago when we first met and were ‘trained’ to help other people face life with a colostomy. We had an inspirational time and were so eager to get out into our communities and be useful, but it was and still is incredibly tough to be recognised by the medical profession as an invaluable adjunct to the well being of an Ostomate.

We were organising the first gathering of volunteers since we formed as the Colostomy Association over two and a half years ago. We didn’t want to give our volunteers any false impression of how difficult and frustrating it was to penetrate the barriers that in some cases surround stoma departments within our hospitals, rather, we aimed to show them how we as ‘past volunteers’ had been brought together, what our aims and ambitions were, how we had organised support groups, how we had helped our stoma nurses with open days and then briefly how we ran the ‘helpline’. (The Colostomy Association recommends that anyone who wants to be a volunteer on the ‘helpline’ has had a colostomy for at least a year and has attended the appropriate CA course.)

Before the induction day, a few of us met at a bar in the Penta Hotel, where we wished we’d had a discreet badge to identify us as colostomates! It was very funny how we all introduced ourselves, the initial worry was overcome. We then headed off to a Chinese Restaurant - it’s amazing how a good meal can act as a marvellous icebreaker!

Around a wonderful table full of fabulous food we all got to know each other our skills, strengths and weaknesses, it really is an invaluable exercise and certainly encourages group bonding!

The following morning it was off to the CA offices. Each person had to talk to the person next to them - this meant that people had to listen carefully to what was being said. Then the person who had been the listener had to tell the group about that person’s colostomy journey. It was so humbling to hear how each of us had coped with illness, work and family and how positive everyone is about what they can do for others. I think that everyone was hoping they would go away with a certificate to say they would be brilliant at listening to the journeys of others who were now ostomates, but as experienced volunteers like us know it takes time to become an effective listener and guide.

Ernie Hulme, Ray Goddard Robin Mills and I worked with the volunteers over both induction days and I have to say that both days were inspirational and thought provoking resulting in a great deal of positive help being proffered by very skilled colostomates.

We have since recruited a number of volunteers as a direct result of these two days who have already produced a brilliant strategy plan, a training programme and a process audit. Committees have been formed and responsibilities delegated. Even sales managers have offered to market the CA so that we learn to sell ourselves to our stoma nurses. So many offers of help! It has been difficult to keep up with the enthusiasm and interest!

Sue Hatton - Chairman

The value of volunteering is immense and irreplaceable.’

‘Volunteering empowers individuals, enhances organisations and strengthens communities.’

colostomy association

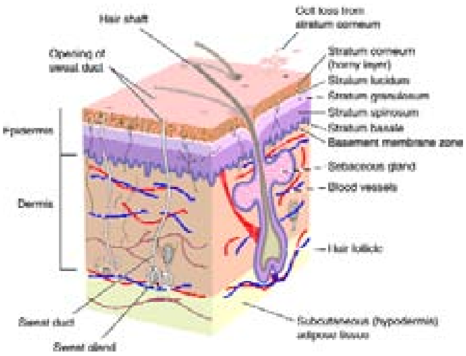
All the Trustees and office staff would like to thank these volunteers for their time and for making the effort to come to Reading and for accepting what we offered and for being so encouraging. We know that with their and your help, the CA will go from strength to strength. We look forward to meeting the next batch of volunteers!

Your skin is amazing...

But do you ever really stop to think about the skin you're in?

At around 2 square metres, your skin is the largest organ you have. There are many folds to allow joints to operate unrestricted and your skin has a whole host of other functions, such as regulating body temperature and keeping out unwanted substances. Did you know, you have around 3 million sweat glands sited all over the surface of your body. That's at least 66 million busy sweat glands in the Manchester United changing rooms after a match!

Your skin is formed in layers and the outermost cellular layer of the epidermis (stratum corneum) is constantly shedding. If damaged, your skin can even rebuild itself - your skin is amazing!



It seems a cruel irony that as your wisdom develops with age, your body begins to deteriorate. Skin is one of the casualties of age: it can become fragile and lose elasticity and with gravity constantly pulling on our bodies changes in our looks and features are inevitable.

Peristomal skin care

As an ostomate, it is vital that you take good care of the skin around your stoma (peristomal skin). As you need to cover the peristomal skin all day, every day with an adhesive pouch or flange it is essential to maintain a good seal between the adhesive and the skin. Your pouch adhesive is almost certainly a hydrocolloid and will seal well against skin - if the skin is in good condition. An episode of damaged peristomal skin can have serious consequences.

In a recent study[1], a staggering 35% of colostomates were found to have a peristomal skin disorder. In my experience, many ostomates accept (and even expect) redness and irritation and do not recognise that they have a disorder.
With good skin care and new silicone technologies, many cases of redness and irritation can be improved or eradicated, before they have a chance to cause a more serious problem that may perhaps require clinical intervention.

A significant recent development in silicone technology may well contribute to the reduction of peristomal skin disorders. Lets find out more...

When you remove an adhesive pouch from your skin, you may be stripping off the outer layers of your skin. This repetitive skin stripping can contribute to irritation and, in more severe cases, even lead to breakdown. By maintaining the condition of your peristomal skin, you are reducing the risk of redness, irritation and possibly more serious damage.
Until recently, medical adhesive removers were not popular for ostomy use. This is not surprising, since early medical adhesive removers contained ingredients such as alcohol, petroleum-based solvents and oil. Each has pitfalls for ostomy skin care.

Alcohol-based adhesive removers

Alcohol is not particularly efficient as an adhesive remover. On a practical level, it often breaks down the adhesive into an unmanageable sticky mess. It is also toxic and readily absorbed through skin. If used regularly it can cause tiny cracks (fissures) to develop on the skin surface. It is, of course, an astringent – drawing moisture rapidly from the proteins in the skin...and (more noticeably important for an ostomate), it stings! Especially when applied to delicate or sore (peristomal) skin.

As you can see, alcohol-based adhesive removers can potentially contribute to dermatological disorders. According to government statistics[2], use of alcohol-based adhesive removers is in steep decline.

Oil-based adhesive removers

Some of you may still be using oil-based adhesive removers. Though not as efficient as silicones, they are unlikely to cause direct damage to skin. But they must be removed completely before the next pouch is fitted and this means additional cleansing. Soaps will break down the oil, but with repeated use, may contribute to skin problems. Again, government statistics[2] have shown a decline since the introduction of silicone technologies.

The new generation of silicone-based medical adhesive removers
The latest silicone technology is now employed to create a new category of super-efficient adhesive removers: silicone-based medical adhesive removers. They can be formulated using 100% silicone ingredients to offer a number of improved and new benefits for ostomates.

Silicone-based adhesive removers are:

- Fast and effective
- Sting free – even when applied to sore skin

The100% silicone formulation also provides the following benefits:

- Almost completely eliminates skin stripping
- Rapid evaporation
- No residue
- Moisturises your skin
- Hypoallergenic

Courtesy of Trio Healthcare Ltd

Several products are now available in aerosol form as well as impregnated wipes. The aerosols are generally the most efficient method of removing a pouch. With the 100% silicone formulation, you simply spray and wait a few seconds for the silicones to penetrate between the adhesive and your skin. At this point, your pouch will probably ‘fall away’ with no trauma to your peristomal skin. One ostomate recently described the effect of the formulation: “It’s like magic!”

The 100% silicone formulation is also available in a wipe, which is designed to remove any remaining adhesive residue and therefore assists the seal when you apply your next pouch.

How does it work?

Silicone is a release agent, which means that it will totally defeat the tack of a pouch flange. But if silicones stay on the skin, the next pouch will not stick. So the silicones we use are formulated to evaporate very quickly. In fact, they evaporate completely (leaving no product residue) so that the next pouch can be applied quickly, securely and without any residual effect from the adhesive remover.

Unlike the older alcohol and oil-based products, it does not have any lasting effect upon the adhesive, so after the pouch is removed the formulation evaporates.
Whilst evaporating, water vapour from the air is drawn to the skin. This action helps to moisturise your skin and is an obvious benefit to you and your skin.

As the formulation tracks under the pouch flange, it temporarily disables the adhesive tack and simply releases the pouch from your skin without trauma, therefore greatly reducing the potential for damage to delicate peristomal skin.

Why 100% silicone?

The adhesive remover is specially formulated using 100% silicone ingredients to ensure the maximum benefit for you. The benefits to you are described above and are proven. Additives may be peripheral to the main function and could lead to unwanted side effects (such as skin irritation). It is unnecessary to include additives, such as colourants, fragrances or other compounds, unless proven to have a beneficial effect.

Prevention is better than cure

Silicone-based medical adhesive removers can significantly contribute to the maintenance of healthy peristomal skin. A peristomal skin disorder can have devastating consequences and can be costly to cure, especially if you consider the nursing time and additional remedial treatments required. As you may well know, peristomal skin disorders can also cause considerable pain and distress.

You may have a pouch change routine that works well for you and you may not experience any redness or irritation. You may not need the speed of a silicone-based adhesive remover. They are not for everyone. But for many ostomates, these products have had a dramatic impact upon their quality of life. Being better informed about these impressive new benefits the100% silicone medical adhesive removers bring, may help you decide to try them or include them in your regular routine.

Facts
About Silicone

- Silicone is often confused with silicon. Silicon is the second most abundant element on the Earth and accounts for over a quarter of the Earth’s crust.
- Silicone is man-made. It is refined using silicon and is available in liquid, cream, emulsion and gel forms.
- Many personal care products contain silicones, such as hair conditioners, shaving products and beauty creams. They are even used in some personal lubricants.
- Silicones are the basis of many primary wound dressings.

References:
1 The Causes of Peristomal Skin Disorders. Per Herlufsen, Anne Grete Olsen, Bente Carlsen, Hanne Nybaek, Tonny Karlsmark and Gregor B.E. Jemec

2 NHS Prescription Cost Analysis Data

Online Communities Offer Ostomists Information, Support, and Connections

Stoma surgery is a life-altering event, but many ostomists have little time to adjust to their new lives. Hospital stays are becoming shorter, which can leave some people feeling unprepared to cope with the resulting physical and lifestyle changes associated with stoma surgery. Many people may also struggle with their self-image after stoma surgery and feel the need to connect with others who understand. Even with attentive support from Stoma Care Nurses, some people with ostomies may still feel isolated and alone and wish they had more resources.

Many helpful options do exist. For example, attending an Open Day event can provide access to medical professionals and the ability to obtain product samples and learn about new products and services from manufacturers. Local support groups can also help people with ostomies form personal relationships and find peers who know what it's like to have a stoma. Resources such as these, however, are not readily available at any given moment; and not everyone may feel comfortable or confident enough to attend these kinds of events.

Fortunately, ostomists – as well as their families, friends, partners and carers – are finding another, growing source of ongoing support: the Internet. Online communication is becoming a popular way to connect to others with similar issues – all from the comfort of your own home. The Web not only offers instant peer connections and 24/7 accessibility, but also offers complete anonymity (if desired) and up-to-date, relevant information. ▶

Welcome to C3Life.com!

Your Ostomy Community Connection Center

Come on in!

Welcome to C3Life.com... where people with ostomies, families, friends and clinicians can come together to meet, learn and share real-life experiences and advice.

Happier, closer, stronger.

Friendly advice for you and your loved ones...

Go further. Do more.

Make going the extra mile a little easier...

Look good. Feel great.

All the right ingredients for a healthy lifestyle...

Work & Life – in balance.

Discover an easier way to balance your work and life...

Read Brenda Elsagher's thoughts on being a national speaker, author, comic, wife, mother -- and a person with an ostomy.

Read Brenda's Blog

Have something you want to discuss with the group? Share your thoughts here and get the conversation going.

Join the Forum

Quick Poll

What is the most difficult aspect of having a stoma?

○ Travel
○ Sexuality
○ Sports and Fitness
○ Dietary Restrictions

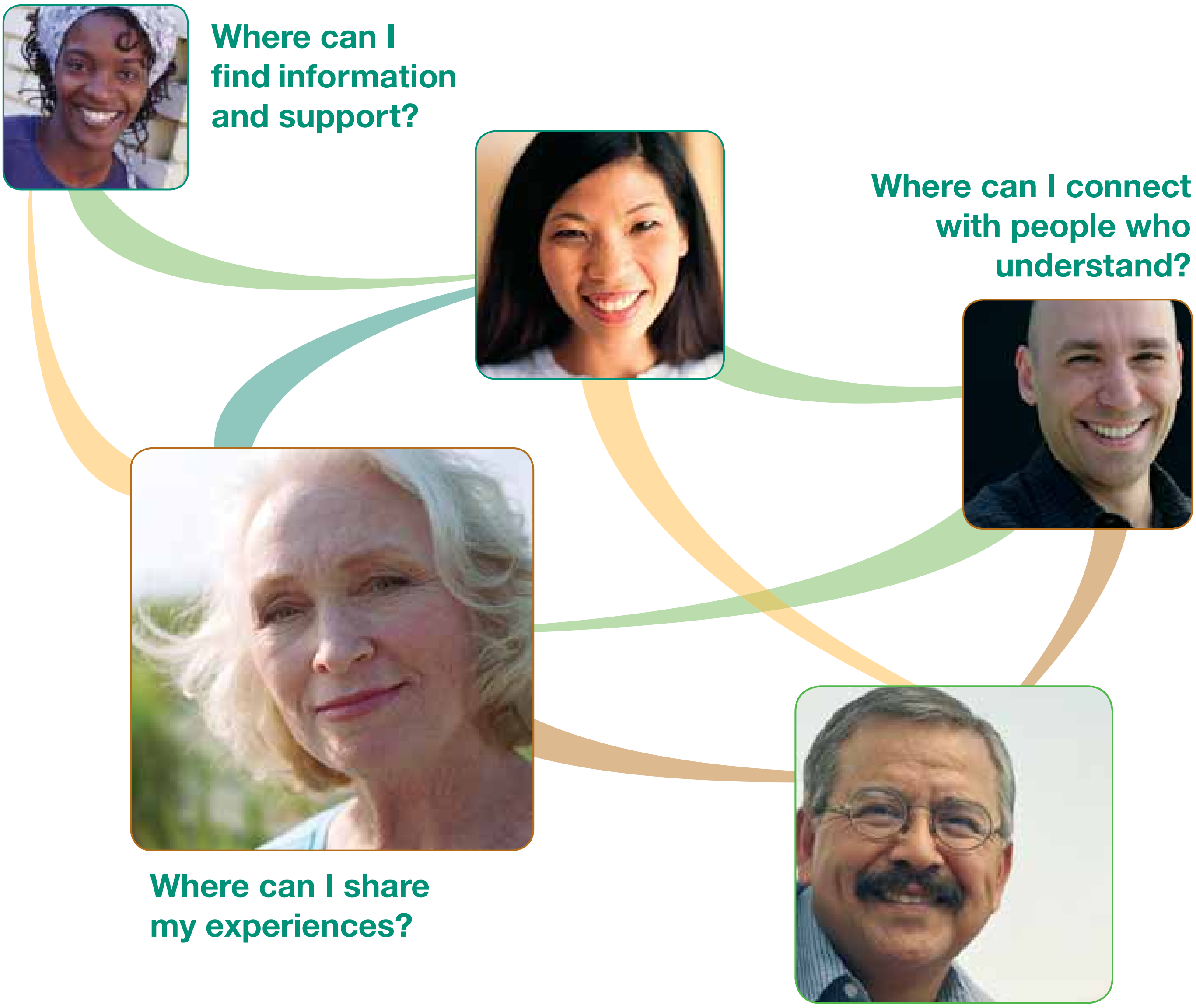
C3Life.com Home Page – Your Ostomy Community Connection Center

Internet users of all ages are looking to the World Wide Web to gain health-related knowledge and support. The growth of websites such as Patient UK, NetDoctor, and NHS Direct is evidence of this trend. Furthermore, according to Prospectiv® — an acquisitions solutions firm — approximately 75 percent of consumers consider the Internet their most trusted source for researching drug information.[1]

Community-based websites are a relatively new way that people are finding health-related information, support, and social interaction. Online communities now exist for a variety of medical conditions including cancer, depression, and diabetes. A few websites for people with ostomies are popping up as well.

One example of an online community for ostomists, their carers, and their family and friends is the C3Life^{SM} website (www.C3Life.com). On C3Life.com, visitors can read about a variety of lifestyle topics, including healthy living, family and relationships, travel, and work/life. They can also find information on ostomy-related health issues, products, news, and events. In addition, if they sign up on C3Life.com, they can pose questions through the "Ask the Clinician Panel" feature, share their thoughts and experiences with peers on an interactive forum, and submit other content, including personal stories, photos, and videos.

The Forum is a very popular feature on the site. In the Forum, C3Life.com Community members can tell their stories, give suggestions, discuss common stoma-related problems, and make friendly connections. Community members have the ability to personalize their communications by including a photo. However, if they wish to remain anonymous, they can post an avatar (a graphical image) to represent them, or no image at all. Screen names, rather than real names, can also be used for the ostomist who desires anonymity. ▶



Cantalibre, Colchester, UK

One C3Life.com Community member, Fred (known by the screen name “cantalibre” on the Forum), is no stranger to online communities. He has a urostomy and ran his own forum for ostomy patients and friends. Unfortunately, he had to shut it down due to other activities and commitments. “I put a message up for anybody who comes to my old site to go to C3Life.com, then I joined the site myself to see what it was all about,” said Fred, 59, who lives near Colchester. “I was quite impressed at how many people were on there, from many different countries, and also [how] they interacted to help each other. Just like one big family, we’re in the same boat.”

Fred said he recommends C3Life.com to anyone looking for reassurance. “If you don’t know who to turn to because it’s late at night or early in the morning, you can go on the site and ask questions straightaway,” he said. Aside from his favourite feature of C3Life.com, the Forum, Fred also said he enjoys the information that the site provides to users. “It’s a brilliant site, it’s just the ticket,” he said. “Knowledge is a great help. The sky’s the limit!”

Lilli, Ashford, Kent, UK

Another C3Life.com user, “Lilli,” is an active participant in the Forum as well. At 76 years old, this ileostomist isn’t letting her age stop her from reaching out to others online. She discovered C3Life.com while in the hospital. “When I came out, my Stoma Nurse had a pamphlet [about C3Life.com] on her desk, and I took it, went home, and clicked onto it,” the Ashford, Kent resident said.

Lilli also said she loves the stories and learnings from other members. “A lot of them had cancer and Crohn’s…and they had to get the operation, but they got to learn to accept it before they had the operation,” she said. “Me, I was rushed in as an emergency and woke up with a bag. I had to learn all the new things that went with it. I now find reading their stories fantastic.”

Users from the United Kingdom and the United States interact on C3Life.com on a daily basis, and that includes Laura from Boston, Massachusetts, U.S.A. The 48-year-old has had an ileostomy for two years. Known as “fuzzy” on the Forum, she is an avid reader and poster. “What I like about it [is] just the fact that there is a forum out there for people with ostomies,” said Laura…“that it even exists.” Laura is one of many participants on the C3Life.com Forum who prefers the anonymity of using an avatar to represent themselves on the site. Laura has chosen a lighthouse to represent her.

Avatar for *fuzzy*, Boston, Massachusetts, USA

Previously, Laura had no one to talk to about her ostomy—at least no one who she felt understood. The C3Life.com Forum gives her the opportunity to converse with people like her. “The number one thing is just being able to talk to people in the same position, hear their stories, be very open and talk about a wide range of issues,” she said. After visiting various other health-related sites, Laura said she doesn’t think any of them compare to C3Life.com. “I find it to be more honest. It’s not all sugary, and people give genuine feedback about things,” she said. “At the same time, there are so many friendly and quite humorous, users. It really breaks up an otherwise bad day.”

The anonymity of C3Life.com is what really appeals greatly to Wendy, an ileostomist from Oxfordshire. “It’s anonymous, but at the same time it has a friendly feel,” said Wendy, 42. “It’s nice to talk to somebody else, but it’s much nicer to talk to somebody else anonymously because you can really open up then. Everybody on there is so glad they’ve found the site.”

Wendy, Didcot, Oxfordshire, UK

Wendy said C3Life.com has become her source for interaction with other ostomists. “I used to go to a support group organised by people at the hospital, but they stopped having it saying we shouldn’t group people like that and allow everyone to be individuals,” she said. “It’s silly—we need people to talk to that have something in common with us.”

Online communities, like C3Life.com, are filling a need for immediate access to ostomy-related information, support and connections. The Web now offers many possibilities for people to connect with others who share their interests and concerns. For both new and experienced ostomists, life after stoma surgery can be challenging; but there’s no need to feel alone when someone to talk to is just a few clicks away.

1. Source: Analysis conducted by acquisitions solutions firm Prospectiv®, and published in “TheInteractiveGuide”; Internet; accessed 31 July, 2008.

Update...

on new stoma care products and services

B. Braun Medical is pleased to offer this stylish wash bag available as a complimentary item to all new customers signing up to the Emerald Prescription Service (home delivery service for your ostomy supplies).

The bag has three useful pockets to keep all your essential ostomy pouches and accessories together and is ideal to take out and about for the day or to keep everything tidy at home. To find out more please contact 0800 163007 or info@bbraun-emerald.co.uk

Dansac launches new Flushable range

Dansac has a history of innovation and is proud to announce its latest development. Designed in conjunction with Colostomists and Stoma Care professionals, the Dansac NovaLife 2 range builds on the proven qualities of the Nova portfolio, and offers a unique Colostomy pouch system designed to suit your lifestyle.

The NovaLife 2 range includes a Flushable pouch designed for easy and convenient disposal. The environmentally friendly inner pouch degrades naturally and offers the freedom to flush as you would have done before surgery. It has been tested to international standards for your peace of mind.

Alternatively you can try the new NovaLife 2 closed pouch which offers a discreet shape and conventional disposal. Both systems include a pre-filter and a Dansac Twin-Filter, and the NovaLife 2 Flange benefits from a fast and hygienic cleaning procedure, offering you the options of 2 pouches and 1 flange. It's your choice! Dansac is dedicated to stoma care. To request free samples of the NovaLife 2 Flushable or Closed pouch, or for more information on the Dansac range of products and services, contact our Patient Services Team on Freephone 0800 581117, or visit our website at www.dansac.co.uk.

Hollister Ltd are pleased to announce that the AF300 filter is now available on Moderma Flex 1-piece pouches, and Conform 2 2-piece pouches.

Since the launch in January 2008, patients have been evaluating the new filter, and we have seen a positive response in patients suffering from ballooning and excessive odour.

74% of patients said that compared to the pouch they normally use, the AF300 pouch ballooned less than, or the same as (with 49% saying less than)

86% said that it controlled odour better or the same as their normal pouch (with 45% saying better)
For more information, call Hollister on Freephone 0800 521 377.

OstoMART Ltd coming soon OstoMIST Mint Drops Odour Neutralising Drops: Highly effective odour neutralising drops and not a masking agent! The drops are effective with the worst odour problems as they contain the active enzyme Nanozyme. The 50ml Dropper Bottle is ideal for those who are reluctant or not able to use a spray.
OstoMIST Mint Drops
Product Code: SPN5 x 50ml Dropper Bottle

New product presentation: OstoSORB – Odour Neutralising Absorbent Gel: Is now available in a Box of 150 x 3grm sachets. OstoSORB sachets are the only discharge solidifying product to contain the highly effective enzyme – Nanzyme. The sachets dissolve on contact with liquid and effectively neutralise odour as they absorb the fluid inside the Stoma appliance. The new OstoSORB box is £6.50 cheaper than the rival bucket of 150 sachets and contains an average 1gram more active ingredient per sachet. OstoSORB is the original sachet presentation and still the best! OstoSORB is suitable for Ileostomy and Colostomy use where the output is fluid. 15 re-sealable packs of 10 sachets in a box.
Product Code:
PFW6 Box of 150 x 3gm sachets
PFW5 Box of 30 x 3gm sachets

Packaging change: OstoCLEAR – Medical Adhesive Remover
Containing Tea Tree and Lavender essential oils. Now available in a new easy to use spray bottle. OstoCLEAR is highly effective in cleaning and removing flange adhesive and stubborn residual adhesive. The Tea Tree oil may help to keep fungal and bacterial infections away from parastomal skin. Trialists loved the fragrance and many said it was the most effective adhesive remover they had ever used. OstoCLEAR is available in a 100ml spray bottle for home use and in convenient sachet form for use whilst out and about.
Product Code:
MRW1 Box of 30 sachets
MRW2 100ml Spray Bottle

Samples of all these products are available now! Call us Free 0800 220 300

Information on new products and services received before 21st November 2008 will be considered for inclusion in the next issue of Tidings.

Ray Goddard
Office Manager, Treasurer
and Trustee

Colostomates' Feedback...

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

If you found it to be superior to what you were previously using or it solved a stoma related problem, please write and tell us about it or e-mail: cass@colostomyassociation.org.uk

Life challenging decision for Claire...

Having problems with her ABS (Artificial Bowel Sphincter) - Claire was offered a colostomy operation by St. Marks Hospital and finding it difficult to go ahead, Claire's daughter decided to help her Mum, searching the internet she came across the Colostomy Association's website Claire made contact and after talking with CA and reading about people's experiences of living with a colostomy - Claire made her decision and this is her story...

Claire pictured at CA Head Office

My first baby arrived in 1971 by forceps delivery. After the birth of three more large babies over a six-year period and much cutting and stitching I was left with a badly damaged sphincter muscle, which left me incontinent.

I had two painful operations to try to repair the damage but these failed, so I had to get on with life as best I could, with a supply of immodium – which made me feel sick. Every outing, visit, holiday with the children were spoilt for me, anxiety ruled, I was always worrying about where the nearest toilet was and would I make it without another embarrassing accident. Even doing my weekly shop was a problem. I rarely made it round the supermarket without having to abandon my trolley and often my children while I rushed for the toilet.

In 1996, I read about the Artificial Bowel Sphincter operation being done at St. Marks Hospital in Harrow. My doctor referred me, and I will always be grateful to St. Marks for accepting me. It improved my life considerably and for six years, with the help of codeine phosphate to slow down my very runny tummy I coped well.

Unfortunately, after six years I had problems and had to have a replacement ABS. The second operation wasn't as successful as the first. I had trouble with the pump sticking shut for anything from two hours to three days. It was very painful and I had difficulty walking. I usually took to my bed until it released. Also, because I had to cut down the codeine the leaking returned.

St. Marks offered to replace the ABS or perform a colostomy operation. I was concerned about replacing the ABS. I suppose I had lost faith, but 45 years ago my mother had a colostomy and all my memories of it were bad. I struggled on for another miserable twelve months unable to make a decision.

Whilst searching on the Internet, my daughter came across the Colostomy Association, fortunately I was lucky enough to live near their Head Office; I made contact with them and was invited to visit, to meet and talk with Beryl Goddard volunteer and CA office helpline administrator. It was so good to be able to explain my problem to somebody who understood. Beryl told me of her experience of living with a colostomy for many years and showed me all the modern appliances available today – nothing like the horrors of 45 years ago. I left the office with as many Tidings magazines as I could carry. I read them from cover to cover. It was an inspiration to read of all those people with colostomies getting on with their lives and, in spite of problems, having good lives. I made my decision.

On April 14th 2008, I had a colostomy operation at St. Marks. I thought once I recover from the operation my worst problems would be over. How wrong I was. The stoma retracted and left me a leaking tearful mess. I had exchanged one nightmare for another.

St. Marks offered to redo the operation. Beryl encouraged me to give it time to heal properly and not to rush to have another operation with no guarantee of a better outcome. Her kindness and experience helped me so much at such a very low time. I also had the support and practical help from my wonderful stoma nurse, Liz Harris at the Royal Berkshire Hospital who gave me so much time out of her very busy schedule.

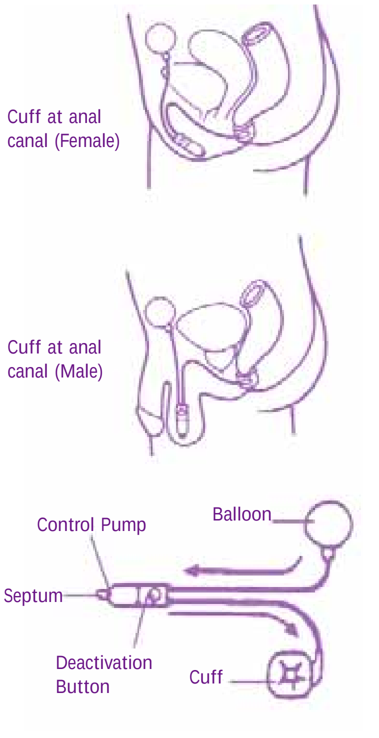
Beryl was right, slowly things began to improve and gradually life changed for the better. I still have bad moments like being out to dinner with friends and thinking I have spilt gravy on my skirt...and I am realistic enough now to know that won't be the last of such moments.

I have had to give up so many things I enjoyed over the years. Now I am beginning to take them back. I have rejoined a local walking group. I can shop without worrying about being too far from the toilet. I always loved to swim and recently swam half a mile. I'm going to try line dancing next. In July I flew to Italy to see my daughter and celebrate my granddaughters birthday – and, yes I was nervous but I did it! I am going to fly to New York next June for a family wedding.

Sometimes, now, when I leave the house I feel something is missing – the anxiety I felt has diminished, but so too has the enormous bag I carted everywhere full of clean up kit and changes of clothes, now I carry all I need in a small bag not much bigger than my make up bag.

I feel so much happier, I want to look good, wear make up, have my hair done, all things I felt for years I didn't somehow deserve. I just wanted to be invisible. On September 11th I took part in the fashion show at the CA conference, and enjoyed it, without worrying about where the nearest toilet was to the runway.
Six months ago, I thought a colostomy was the worst thing that could happen to me, but now in spite of the difficult times I know differently. As another colostomate said 'no one wants to wear their bum on their tum' but it's given me back control of my life and I'm enjoying it so much.

Diagram shows an AMS implant - Artificial Bowel Sphincter (ABS) Prosthesis



‘Find information’ on the CA Website

If you are searching for helpful information like Claire’s daughter why not take a look at the Find information area on the CA Website...

The new website is designed with a more streamlined structure and consistent appearance that is user friendly and easily navigable by tab headings organised by the following categories:

- Home
- Who we are
- Get involved
- Find information
- Donate
- Contact us

Lets look at...
Find information - at a glance:

This area offers a wealth of detailed information available to all, written for colostomates, their families and their carers.

How to use ‘Find information’: Each panel has built in links which take you on to other pages of articles, literature and factsheets, stoma care guides, hints and tips. There is also an A-Z glossary which is information specific to ostomates. We are especially pleased to be able to offer a page for young colostomates.

So why not explore today...

Find information – at a glance

http://www.colostomyassociation.org.uk/find-information/find-information-at-a-glance.aspx

Headlines

Home Register Login Contact Us

Search our site:

Dedicated to Colostomates, their Families and their Carers

Home | Who we are | Get involved | Find Information | Donate | Contact us

You are here: Find information > Find information - at a glance

Find information - at a glance

Welcome to our information pages - this area offers at a glance, a wealth of information available to you, specifically written for colostomates, their families and their carers.

How to use this page - each panel has built in links which take you on to other pages of articles, literature and factsheets, stoma care guides, hints and tips, plus a comprehensive information specific A-Z glossary for ostomates, we are especially pleased to offer a page for young colostomates and other resources that we hope will assist you in your search for information.

Feedback - we welcome your ideas and suggestions for this area, we aim to build a centre of excellence, available to all. We will be constantly updating this resource to keep abreast of new ideas, product developments and medical information.

need advice or just want to talk? call our 24hr helpline 0800 328 4257

Medical articles:
The following information will be available soon...
- Where and what is the colon
- What is colon cancer
- Symptoms and causes
- Diagnosis and treatment
- Preparing for medical visits
- Pre and post surgery

Stoma care guides:
Click on a each heading to go to a different guide...
Guide 1
Colostomy management
Guide 2
Getting back to normal
Guide 3
Understanding feelings

FAQs:(Frequently asked questions)
Welcome to our general questions section - this will be available soon.
Want to know more...
Click here>

real life experiences
providing clear information

Hints and Tips for you:
Many of these helpful ideas have been sent to us by our members and readers of Tidings Magazine. They deal with practical issues of day to day living with a colostomy, we hope you find them useful.
Learn more...

Glossary A-Z:
Click on a letter to find a definition e.g T - Template

Factsheets:
Here are some examples of our factsheets...
- Clothing
- Deodorant
- Insurance Companies
- Support Garments
- Swimwear
- Underwear

Learn more...

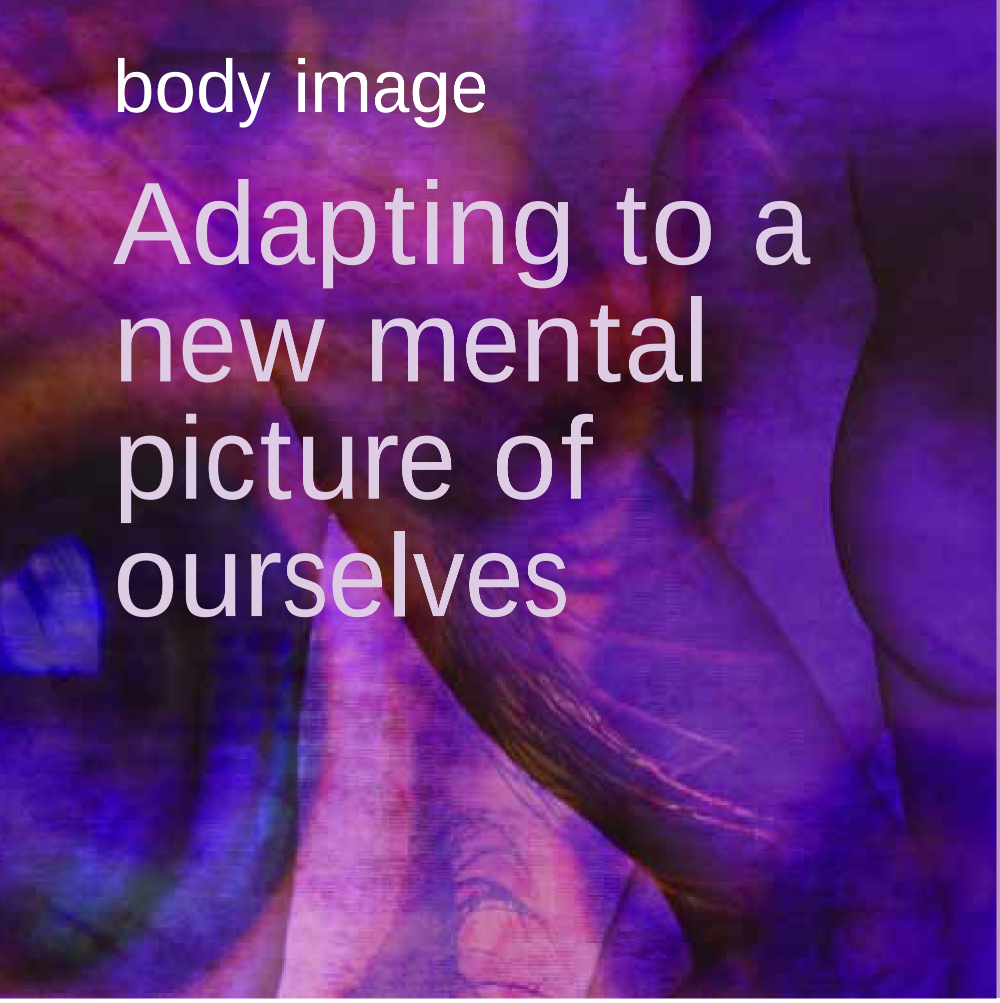
Literature for you:
Click here> for more info
- Healthy Eating
- Introduction to Irrigation
- Living with a colostomy
- Rectal Discharge
- Rectal Pain
- Travel Advice

Tidings Magazine: Back Issues
The following issues are available for download - **for more info>**

Tidings Issue 1
Tidings Issue 2
Tidings Issue 3
Tidings Issue 4
Tidings Issue 5
Tidings Issue 6
Tidings Issue 7
Tidings Issue 8
Tidings Issue 9
Tidings Issue 10

Feedback - we welcome your ideas and suggestions for this area, as we aim to build a centre of excellence, available to all. We will be constantly updating this resource to keep abreast of new ideas, product developments and medical information.

http://www.colostomyassociation.org.uk/find-information/find-information-at-a-glance.aspx



Adapting to a new mental picture of ourselves

We hear much about body image in today's media, models trying to be a size zero, obesity in children, young girls heavily influenced by celebrity culture to the point where they become anorexic or bulimic.

What does body image mean to the stoma patient?

Adaptation to the stoma is defined in the terms of the patient's subjective appraisal of the quality of their lives, the degree to which they resume their social activities and their psychological adjustment to their stoma (Wade,1989)[7].

Body image is also the mental picture each individual has of their physical being. It begins to develop from birth, when the infant is not aware that he is a separate being from his mother. He learns about various parts of the body, how they function and how to gain control over them. This learning process continues to evolve throughout life and is influenced by the relationships we have with others, our everyday experiences and sometimes events that occur over which we often have no control.

For the stoma patient, the raising of a stoma may lead to the alteration of the mental picture they have of themselves. The intensity of emotional reactions to body changes are related less to the severity of the disability than to the assigned importance of the structure, and this appraisal depends, among other considerations, on the individual's immediate social situation and past experiences (Black, 2000)[1].

Many contributing elements may affect the patient's ability to adapt to the alteration in their perceived body image, and these are relevant to both the patient and the patient's family. These may include, but are not limited to, the disease process, diagnosis, treatment, medical and nursing care within the hospital and the return to their community.

Most people feel that bodily elimination is a private function, best managed in one's own home. Excretion and excretory behaviour are rigidly controlled in each culture and in each society, and in Western societies there are strong prohibitions on the uncontrolled passage of urine and faeces. Most people deal with their change in body image by initially denying that it is happening to them. Littlewood (1985)[4] suggested that in Western culture if one defines oneself as sick, when acts of excretion occur in the wrong place, such as leakage or failure of a stoma bag, they can be forgiven or managed in such a way that the patient is not socially ostracised. If the patient cannot declare oneself as sick, either because they cannot or do not wish to do so, appliance failure or incontinence can reduce one to a childlike state.

The psychological implications of having a stoma have been likened to passing through the stages of bereavement, mourning for the loss of the body part. Parkes (1972)[6] suggested that there were 5 stages through which the patient with body image change passes:

- Realisation; avoidance or denial of the loss followed by experiences of unreality or blunting.
- Alarm; characterised by anxiety, restlessness, fear and insecurity.
- Searching; characterised by acute episodes of anxiety, panic and preoccupation with loss.
- Grief; feelings of internal loss and mutilation.
- Resolution; characterised by efforts to construct a new identity.

When looking at the literature that describes body image and it's change especially after stoma surgery, several common themes occur. As early as 1956 researchers were saying that an immense price is paid for the cure and that price not only incorporates physical discomfort, but also psychological and social trauma. In 1971, Devlin, a colorectal surgeon from the North of England looked at the effect of surgery for colorectal cancer and found how devastated the patients with colostomies were and how complicated life could be. More recently other researchers have found that there is a relationship between quality of life and self esteem among patients with stomas.

The length of time it takes to adapt to living with a stoma varies but it is estimated to be about a year with the trajectory peaking at around 9 months after surgery. For many with a temporary stoma these are often reversed within a year. For those having a stoma for inflammatory bowel disease there is the notion of ‘trade off’ for having either cure in the case of colitis or remission in the case of Crohn’s disease. Wade (1989)[7] considered that there were several points in adaptation to having a stoma and living with ones changed body image.

- Adaptation may be more difficult for older people.
- Patients who are relatively free from symptoms may adapt more readily than those who are not.
- Patients who have access to a stoma care nurse may adapt more readily than those who do not.
- Women may adapt less readily than men.
- Patients who have the support of a spouse may adapt more readily than those who do not.
- Patients who have been ill for some time may adapt less readily than those for whom the onset of illness was sudden.


Courtesy of Dansac

Some patients, after stoma surgery wonder how others will respond to them and what the response will be, this is a natural reaction, you are intensely aware of your body image change and because of this, you may feel vulnerable, you may also feel that everyone is looking at you, even though this is not the case. After surgery your new appliance may feel bulky and awkward and you may feel that others can see it, but in fact it will not be recognisable to others when you are fully clothed (Dansac, 2001)[2].
How we feel about our body plays a crucial part in how we communicate with others, one of the many ways in which we communicate with others is via our body. The way we move and present our bodies sends subliminal signals and messages to others, which are then returned, so even though you have had surgery and may not feel too good, developing a positive self-image will help you regain confidence and acceptance of your body.

Acceptance of the stoma may be considerably influenced by people who are significant in the stoma patient’s life (McVey et al 2001[8], Wade 1989[7]). It is not uncommon to find a new patient assuming that his partner will be unable to cope with looking after his stoma. Support enabling him to ask his partner if she would like to see an appliance being changed (and thus see the stoma) before he leaves hospital often reveals that the partner is very pleased to accept this invitation. Each couple should be allowed to make their own decision: insistence that the partner must watch an appliance being changed can do more harm than good as the patient may then not really believe his partner does accept the stoma. It must also be remembered that not all couples appear naked in front of each other, and providing the partner with a full abdominal view complete with stoma may violate that couples normal rules of behaviour. However, in many cases, where it is appropriate, a change of appliance carried out by an informed nurse who answers any questions raised by patient or partner can do much to start the patient on the road to acceptance of his new body image.

Adapting to body image change can impact on all aspects of life. Holidays are an important social event and many patients feel that they cannot go away again. Many patients feel that they do not have the confidence to go away and feel difficult or embarrassed when staying away from home in a strange place or with friends. Support and encouragement and informative literature can help the patient gain confidence and enable them to overcome these difficulties.

In your social world there will be people who are close to you, those who you wish to tell about your operation and there will be others for example at work or socially who will not be familiar with the details of your surgery, but know that you have been away for a while. Meeting these people after a long period of illness and recovery can be an anxious time. The best way to reduce your anxiety is to prepare yourself before meeting people with what you will say. It is up to you whom you tell and what you tell family and friends. Often you will feel weepy when telling people about what has happened to you, talking may enable you to come to terms with your experiences more quickly, and as time goes by this may help you feel stronger and more able to discuss everything in a rational way.

After surgery and recovery from your operation, you will be able to slowly build up to what you used to do and be able to return to your usual activities. In the early weeks your emotional and physical responses may be very intense and surprising to you, and to your partner and family but in time you will learn how your body now reacts and how you react to other people.
Although Devlin[3] (1971) suggested that patients with a colostomy felt devastated, more up to date research by Padilla and Grant[5] (1985) suggests that there is a relationship between quality of life and self-esteem among individuals with a stoma and that quality of life and self-esteem were indicative that the overall ostomate population had positive perceptions about their body image after surgery.

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References:
1 Black P, 2000. Holistic Stoma Care. Balliere &Tindall. London.
2 Dansac Ltd, 2001. Body Image after Stoma Surgery. Histon, Cambs.
3 Devlin HB et al, 1971. Aftermath of Surgery for anorectal cancer. BMJ iii;413-418.
4 Littlewood J, 1985. No flag day for incontinence.Self Health.September:32-34.
5 Padilla G & Grant M, 1985. Quality of life as a cancer nursing outcome variable. Advances in Nursing Science;8:45-60.
6 Parkes C, 1972. Bereavement: studies of grief in adult life. Pelican, Harmondsworth.
7 Wade B, 1989. A stoma is for life. Scutari Press, Harrow.
8 McVey J, Madhill A, Fielding D 2001 The relevance of lowered personal control for patients who have stoma surgery to treat cancer. British Journal of Clinical Psychology 40:337-360 9 Wade B, 1989. A stoma is for life. Scutari Press, Harrow (McVey et al 2001, Wade 1989).

"I've never felt or looked so good - looking good - made me feel good"...

The phrase 'Clothing maketh the man' is often used to imply that appearances count for a lot! I had no such thought in my head when I agreed to be a model for the fashion show that was being organised by Maureen Kelly-Smith (Public Relations Manager) of SecuriCare.

Earlier in the year Maureen had organised a similar fashion show for the Ileostomy Association which proved to be a great success. Maureen offered her invaluable services to the Colostomy Association, her offer was taken up immediately and planning for the event began in earnest.

The theme for the Fashion Show was to be "Simply the Best – Dressed." Maureen approached John Lewis of Reading to ask them if they would be interested in sponsoring the fashion show, they agreed.

I was thrilled to be asked, because I believe that there is no reason why having a stoma should make people feel or dress differently. Many people feel that their clothes are an expression of who they are and enjoy wearing and choosing clothes to fit in with both their sense of themselves and their lifestyle. Some stoma patients often show concern that their usual clothes will not accommodate stoma appliances discreetly and assume that their clothes will need to be baggy and that this will be a necessary part of their future life – this is simply not the case.

I have always admired the many members of the Association that I have met at open days or gatherings, who have never let their stomas make any difference to their wardrobes. I thought mine hadn't until I was introduced to the personal fashion shoppers of John Lewis!

Shelley and Caroline, fashion advisors for the John Lewis store in Reading, visited the offices of the Association and discussed with Ray Goddard and Maureen how the clothes for the individual models would be chosen and how it would be organised.

Appointments were made for us to attend the store, meet the fashion advisor and try on several outfits until we agreed on two outfits which we would be happy to model. This was the same for the men and women!

Beryl Goddard was the first one to come back and report what a wonderful experience it was. Beryl was thrilled and delighted with the outfits she was to model and I carried her enthusiasm with me when it came to my turn to visit the John Lewis store. I duly made my way to the offices of the Personal Fashion Advisors and was greeted very warmly by Caroline Shaw – who took care of me. There were two rooms, one an outer office comfortably furnished and a changing room, curtained off to provide privacy.

Caroline explained that we would walk through the fashion department, stopping to look at, and choose three or four different outfits to try on – to see what suited me or what I thought I would like to model.

In the past, I have walked through the fashion department of John Lewis a hundred times, looking, trying on and sometimes buying – but more often than not rejecting items that I thought would look good but turned out to be a disaster! No such thing happened on this visit.

Caroline walked me through a department where there were beautiful dresses – and immediately picked out a gorgeous soft flowing chiffon type dress, with a shaped hem and jewelled shoe string straps in the loveliest lilac and pale mauve hues! A few minutes later she had the dress and a soft lilac shrug over her arm and we set off for another department. Her next choice of clothing was made in no time, this time a skirt, jacket, trousers and blouse joined the items already draped over her arms.

The first outfit I tried on was the dress – it slid beautifully over my shoulders and flowed gracefully down my body – held by the jewelled straps. It was just so stunning that I could hardly believe I was wearing such a dress. With the little shrug on, I walked out into the office so that Caroline could assess the result. We both agreed that it was perfect – I felt very reassured that I would look good in the first outfit I was to model.

I must admit I had to keep checking the mirror because I looked so different! I had never worn a dress like it and if it had been left for me to choose I would have walked straight past because I would have assumed it would show every bump and lump! How wrong I was.

My second outfit produced even more oohs and aahs – because the colouring was unlike any colour I had worn before, it looked fantastic. The skirt was full and patterned gunmetal grey and lime green, and was teamed with a lime green fitted jacket. Immediately, I noticed I had a waist! Underneath the jacket I wore a cream top - and after a quick visit to the jewellery department – I was teamed up with a string of large pearls and matching shoes.

I had never felt or looked so good – and looking good - made me feel good. Confidence oozes out of you when you know you are looking your best, you start to believe in yourself and your self-esteem improves.

I didn't even glance at the other outfits on offer – because I knew that with Caroline's help and reassurance these two outfits were perfect for me, for my colouring, my shape and what's more for my well being.

Caroline and I discussed the reasons why I wouldn't have chosen the outfits left to my own devices. She explained that even bringing a friend to help you choose new clothes does not change your attitude to colour and shape – because they see you as you see yourself. You tend to stay with the same ideas because that is what you have grown used to. With Caroline's expertise and knowledge of fashion she was able to look at me and know instinctively what would suit me.

The service at John Lewis is free and I would recommend anyone and everyone to ask at their fashion stores for an appointment with the personal shopper. They really can help you choose clothes that suit not only your body but also your budget so you do not need to commit a great deal of money to look better or different. I shall certainly be asking to repeat the experience.

Jackie
CA volunteer

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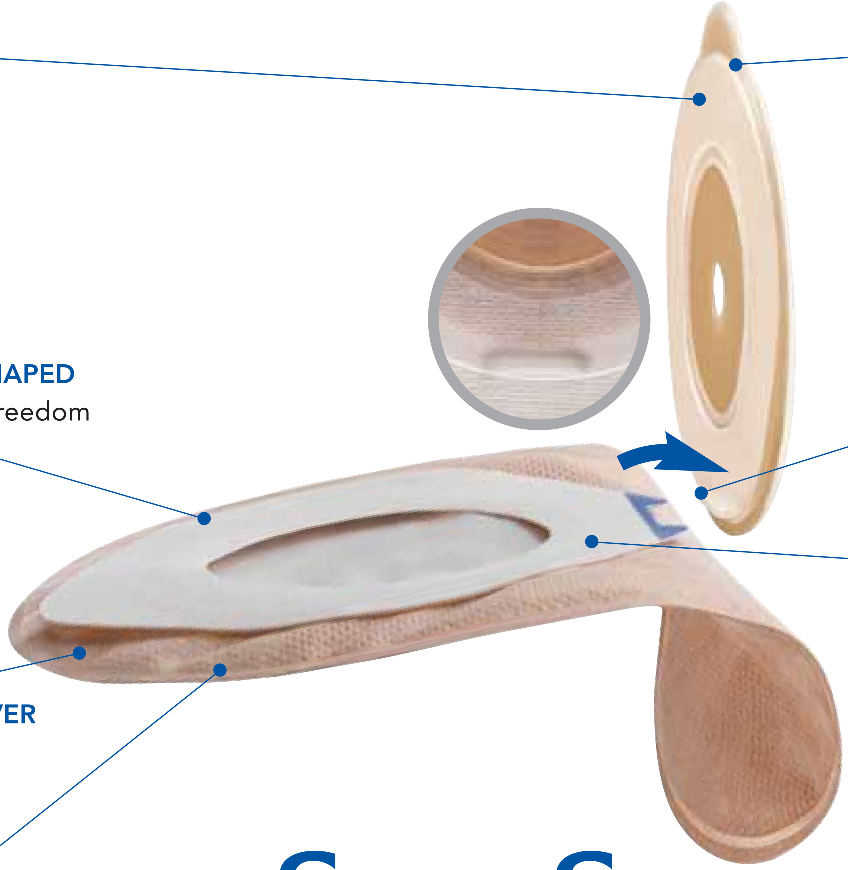

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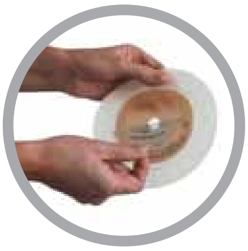

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Style and Personality

John Lewis Reading Fashion Advisor Shelley Viveash provides her top style tips...

Shelley Viveash
John Lewis Reading Fashion Advisor

Clothing is a silent but very powerful communication tool; clothes can camouflage, cover up and build our personal image. Clothes can reveal positive aspects of our personalities and help to give us self-assurance and build confidence and at times clothes are the only visible clue to our personalities and lifestyle.

A person's first view of others is often based on a first meeting, their appearance and what they are wearing can often influence and help to formulate an opinion whether it's right or wrong.

By changing any part of your appearance such as hairstyle or clothing you can change the total image others have of you and you have of yourself. And when it comes to looking good it's not your size or shape that matters, it's the fit of the clothes and how you feel when you are wearing them.

Clothes should boost your confidence and help you make the most of your shape and by understanding how colours work together, flatter your body.

Being in the fashion industry for many years and knowing how important body image is, I was devastated when in March 2000 I found out that after my bowel operation I needed a colostomy bag.

I felt life would never be the same again. Yes, the usual things went through my mind. I thought it was embarrassing and that everyone would be able to tell. Thankfully these feelings soon passed and I learned to not only live with my stoma, but to enjoy clothes again too.

As a Fashion Advisor at John Lewis of Reading, I know that whatever your personal body issue, it's all about finding the right style for you as an individual. In this article I have passed on some tips that you may find useful.

So, what happens at an appointment?
When you arrive we have an informal chat about your lifestyle. We then take you to areas of the fashion floor that suit your height and size and we will select a few garments together. While you are beginning to try the clothes on in our spacious fitting room we can assess the colours and styles that will suit your body shape.

We then return to the fashion floor selecting garments to meet your requirements and budget. This can be anything from individual outfits for a special occasion to a whole new wardrobe, while you relax with a drink and magazine!

We can even discuss everything from packing a capsule suitcase for your holiday, posing for the camera at that special occasion or simply have a chat about the latest trends.

For information on a John Lewis store near you why not check out the John Lewis website: www.johnlewis.com or if you live in the Reading area and would like to make an appointment with the Reading store fashion advice team simply call: 0118 9502690 and ask for Shelley Viveash, Sara Carter or Caroline Shaw.

We look forward to seeing you!

Here are Shelly's top tips to help you get it right just like the models pictured above from the CA fashion show...

Colour - The right and wrong colours
You'll know the colour is right for you when:

- Your face appears to be lit from underneath
- Your skin appears smoother, lines and blemishes are minimized
- Your eye colour is enhanced
- You will notice you more than the colour

You'll identify the wrong colours when:

- There are dark or coloured shadows around your neck and chin
- Your complexion looks uneven in colour
- The colour stands out more than you

When you have a stoma, your waist is the part you worry about most.

For high waisted:
Try dropped waist-line, skirts and trousers without waistbands, low slung belts, long jackets and tops, volume or pattern on your legs, long tops and long skirts will all create the illusion of lowering your waist.

Long rise and average to short legs:
Low waistlines, skirts and trousers without waistbands, low slung belts, high heels, long jackets and tops with narrow skirts or trousers can all create the illusion of lowering your waist without shortening your legs.

For men: (matching colours or same colour tones are good for illusion)
Vertical necklines. Push your belt down lower than your natural waist - you gain a half-inch longer waist if you tuck in your top over the belt for disguise.

Low waisted short rise and average to short legs: Belts and tuck-ins, short tops, minimal detail in the rise area, short jackets with long or short skirts, straight waisted or belted dresses, long jackets with short skirts or narrow trousers and high heels all create the illusion of raising your waist without shortening your legs.

Long rise and short legs: Belts and tuck-ins, short tops and jackets, details such as pockets in the rise area, keeping to one colour from waist to toe, high heels and straight waisted or belted dresses create the illusion of raising your waist and lengthening your legs.

For men: Wide necklines detract attention from the waist. Short jackets and double-breasted jackets create perfect illusion.

Thick or wide waist: Baggy tops, boxy cardigans. Trench coats, shift dresses, navel-deep Vs, wrap tops, short zip front jackets, frock coats and wrap dresses. Fitted dresses in soft material with small print, dropped waist denims. To avoid accentuating the waist try wearing outfits that change colour at the waist.

For men: Good styles-use medium size belt without large buckles. Long, loose fitting tops. Tops that hit hip-line create good illusion. Full leg trousers-flared.

Accessories: Shoes and boots will update your look. Bags and hats are also key items and scarves will introduce colour.

Hats: Hat brims should not extend beyond your shoulders. Complement your face with your hat shape. Rounded crowns and brims in soft fabrics suit round faces.
Dark colours cast a shadow over the face, square or rectangular faces look good in flat crowns and straight brim. A completely co-ordinated outfit with matching hat looks contrived; a complimentary or contrasting colour adds interest.

Scarves: Skinny scarves will look out of proportion on a larger frame. Don't tie scarves under chin if you have a short neck. A long thin scarf draped around your neck will make your body appear taller and slimmer.

Belts: You need a waist to wear a belt. Narrow and lightweight belts are best on petite to average women. Wide statement belts are best on average or tall frames. Belts must work with the overall look.

Footwear: A high or narrow heel adds length to the leg. If you are wearing a short skirt a lower heel will make legs look longer. Low fronted shoes give the illusion of longer legs and narrower ankles. Closed shoes shorten the length of the feet and legs. When choosing shoes with straps bear in mind that low t-straps work for most people, while ankle straps will only look good on long legs and slim ankles. When buying boots make sure they stop at a narrow point on your legs. Ballet pumps are good for anyone with average to long legs and thin ankles - satin, velvet or beaded are good for the evening, teamed with long skirts or trousers.

Bags: Your bag needs to balance with your overall frame. A large bag will overwhelm a petite person, where as a tiny bag will look wrong on a larger frame. The shape of your bag needs to follow the line of your body. Don't take a casual bag to a business meeting. Don't take a formal leather handbag to a Gala Dinner. Before you buy a handbag, look in the mirror and check it looks right for you.

Your body frame:
Petite: Wear one colour from head to toe, don't wear too much volume. Wear small print patterns. Smaller accessories. Minimal texture and bulk. Try to avoid large brimmed hats and oversize scarves such as pashminas.

Average: You should wear accessories that balance your scale. Average size patterns. You must follow your body shape.

Tall: Use colour to break up your height, by wearing differently proportioned clothes you will look more balanced. Large bold prints and statement accessories. Heavier weighted fabrics or finer fabrics layered.

Swimwear and underwear for people with stomas is a specialist subject. If you want to know more register online at Colostomy Association website and go to the Find Information section to download the relevant factsheet or contact CA on 0118 939 1537.

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Supporting 'young people' living with a colostomy at school - the negatives and the positives...

Among the numerous telephone calls we receive on the helpline, are many from anxious mothers or families with children of school age who have a colostomy. There seems to be a distinct lack of advice and support for the families of children attending school at any level.

We are hearing very sad stories of children with a stoma being side-lined at school. Some even placed in a classroom on their own because other children won't sit by them. Name calling is also an issue. No-one should be made to 'feel different' or to suffer just because they have a colostomy. School is after all, a place for learning, perhaps schools should recognise there is a need to teach understanding and compassion as well as the ABCs.

Schools also have a legal responsibility towards children with medical needs - we must try to educate the schools, their staff and pupils to accept children with colostomy's.

Some schools and parents need to be made aware of the Individual Education Plan (this plan is designed to set out strategies which can be used to meet each child's identified needs). It is important that all parties meet to discuss a child's needs - school staff, parents and if possible a health professional.

Parents – especially those who have already had difficulties within the school system – may find it difficult to approach the school again. This is when it is especially important to have support from 'outside'. We want to make all head teachers and other teaching staff aware that their attitude if negative towards any child with a medical problem can seriously impact on that child's school attendance and their home life.

For anyone, being made to 'feel different,' by those around you is an upsetting experience. Some children with a colostomy may find themselves excluded from school activities, such as sport. It is important for the school and staff to recognise there is no medical reason - why a child with a colostomy should not play sports or do anything else he or she feels comfortable with.

Children who have been through the trauma of needing a colostomy show great fortitude and courage. Teachers should be made aware of their experiences and the symptoms suffered, some of which are outlined below:-

- An urgent need to go to the toilet
- Diarrhoea
- Severe abdominal pain
- Extreme tiredness
- Nausea
- Passing blood with stools
- Lack/loss of appetite
- Weight loss and failure to grow.
- Suffering the embarrassment of having an accident and worrying about smell.

Although receiving a colostomy frees the child from these symptoms. It takes time to overcome and recover from a colostomy operation. Even some 'grown-ups' find it hard to come to terms with 'living with a colostomy' – how much harder must it be for a child to cope?

Psychologically, it is very difficult for children to deal with the embarrassment of having a colostomy and the need to wear an appliance. They may be very concerned with how they look, whether it will smell, or how they are going to cope with it – all perfectly normal questions – asked by all 'to be' colostomates. With the correct support from family, friends and school authorities these doubts can be overcome. What needs to be emphasised to schools, is simply this – 'having a colostomy gives people freedom to get on with their lives'.

A child with a colostomy needs to build confidence and knowing that their school supports them will help. Schools should provide designated toilet and disposal facilities for used pouches. Indeed, everything should be made easy for the child. Some children may want to keep the matter of their colostomy private and this should be respected.

Children who have any kind of medical condition need to be encouraged and supported by everyone around them. The children themselves are plucky individuals – let us all ensure that this is recognised.

Having a colostomy doesn't bother me at all...

I feel I'm a 'normal' person having lots of fun, in fact some times I forget I even have it.

I'm a little girl who loves dressing up and if it means my tummy is showing I just pull my skirt up a bit to cover my bag, it's no big problem. I prefer dresses as they're a little comfier but we never buy special clothes as there's no need. I'm just as fashionable as all my friends. The only time you might see a bump in my clothes is when I wear my leotard for ballet or gymnastics. I sometimes wear a ballet skirt or leggings with my leotard to help cover things but no one ever asks about my bump so it can't be that noticeable. One thing's for sure, you definitely can't see it when I'm skiing!!

> "School is brilliant as all my teachers help and support me. I'm just like any other member of the class. Some of my friends know about my bag, others don't. That is the nice thing about a colostomy. You can choose who you tell. All my class know I've been in hospital and think I'm very brave, they are really understanding."

I don't like bullies and I won't stand for it. People can say nasty things but I'm prepared for that and I have some very special friends who stick up for me. Having a colostomy is nothing to be ashamed of. It's not my fault I have one. I can't change it, but that won't stop me living a fun and exciting life.

Brooke Taylor – Age 7

Websites specifically for children and their families...

www.convatec.co.uk
Provides a link "just for kids" section. This site is designed to act only as a guide for parents and professionals.

www.smiliespeople.org.uk
Forum set up by Ollie, a teenager who has an Ileostomy.

www.vicnet.net.au/youinc
YOU (young ostomates united)This is an Australian website but young ostomates may find the stories helpful as many are written by teenagers.

www.ostomates.org
Shaz is an Ileostomate from Western Australia and had her surgery at the age of 10. Her website is designed to be an interactive support page for new and experienced ostomates. It is for ostomates by ostomates.

www.ostomylinks.co.uk
This website offers links specifically for children, teenagers and young adults. Links are available for parents. Includes discussion boards and ostomy chat rooms.

www.ostomy.support.info
This website offers interactive support, product information and lifestyle guide.

www.colostomyassociation.org.uk
The Colostomy Association is working hard to change people's attitudes to a colostomy. This is especially important for children-we are here to support families with children who have a colostomy and to help educate those who do not understand 'what it is like to live with a colostomy'.

Pilates - Exercise and Ostomates

> "The attainment and maintenance of a uniformly developed body with a sound mind, fully capable of naturally performing our many daily tasks with spontaneous zest and pleasure."
> Joseph Pilates

You may have heard of Pilates (pronounced pi•la•tiz) and the benefits this type of exercise has to offer. Having a colostomy has never stopped me from taking and teaching regular exercise and that includes the Pilates method.

The Pilates method of exercise, was developed in the early 20th century by a man called Joseph Pilates. There are many people who follow these exercises and many instructors teaching them in the United Kingdom.

The exercises focus on the core postural muscles which help keep the body balanced and help to provide support for the spine. In particular, Pilates exercises teach awareness of breathing and alignment of the spine, and aim to strengthen the deep torso muscles which keep your tummy and back stronger and can sometimes help in preventing an abdominal hernia.

As a colostomate of five years and a Pilates Instructor, I have found this type of exercise to be especially suitable for me, as the movements can be fairly easily adapted to suit the individual and can be very gentle and non-threatening. I was lucky to recover from the surgery within a short time frame and was teaching again after 12 weeks. It felt quite scary facing a room full of people who were all looking at me and I was concerned they would all be able to see my colostomy bag! In fact only a few people knew what operation I had undergone and other people had no idea as the bag could not be seen (even in skin tight Lycra)! My worst fear was the stoma making one of its unannounced loud sounds that remind me of an elephant. But most of the time I could sense when this was about to happen and put my hand over the stoma to muffle the sound. Obviously undergoing any major abdominal surgery is going to affect your ability to exercise, but my stoma has never stopped me doing all the things I did before I had it. I'm just very careful to exercise sensibly, cautiously and most of all within my capabilities.

The Pilates mat program follows a set pattern, with exercises following on from one another in a natural progression. Beginners start with basic movements and build up to include additional exercises and more advanced movements.

People who enjoy Pilates say they stay with the program because it's diverse and interesting. You can do fewer repetitions of a number of exercises rather than lots of repetitions of only a few. Joseph Pilates intended his exercises to be something people could do on their own once they've had proper instruction, cutting down the need to remain dependent on a trainer.

If you decide to try out a session, get the most out of your Pilates workout by thinking about the following:-

• Focus Your Mind - Pilates is designed to combine breathing with your body's movements. Instructors teach ways to keep breathing and working together with the exercises. You will also be taught to concentrate on your muscles and what you are doing, aiming to unite your mind and body, which can also help to relieve stress and anxiety.

• Be Comfortable - Wear comfortable clothes (as you would for yoga - shorts or track suit bottoms and a T-shirt are good choices) and usually Pilates is done without shoes. If you start feeling uncomfortable, strained, or experience pain, you should stop (as with any exercise).

• Flow - When you perform your exercises, avoid quick, jerky movements. Every movement should be slow, but still strong and flexible. Joseph Pilates worked with dancers and designed his movements to flow.

• Enjoy! - The nice thing about Pilates is you don't have to break into a sweat if you don't want to. Pilates is primarily about strength and flexibility, so combining other types of exercise is just as important. As well as Pilates try to incorporate a form of aerobic exercise like swimming or brisk walking 2 or 3 times a week.

If you are interested in participating in a session, check with your local leisure centre (details can usually be found on your local council's website) as they will have a whole list of things you can try that include Pilates. Your local Primary Care Trust should have a list of Health Walks in your area – a great way to get fit and meet some new people.

If this article inspires you to try Pilates, start slowly and steadily, trying not to overdo anything, until you find a level you are comfortable with. Some gyms have specialist programmes for people recovering from surgery or with specific types of illness, disability or medical condition. You may wish to discuss this with your GP, Practice Nurse or Stoma Care Nurse, as they may be able to refer you onto one of these schemes.

On a positive note, the benefits of regular exercise are many, regardless of having a stoma or not! You should aim to do at least 30 minutes of moderate (non-intensive) physical activity five days a week. Moderate exercise can include going for a gentle walk, or doing some gardening. However, if you have been inactive for a long period of time, try to build up to 30 minutes a day over the course of several weeks. Also, avoid high-impact exercises, such as sports that involve hard jolts to your body, for example football or squash. Remember to always start an activity slowly and gently, always warming up before you start and cooling down at the end.

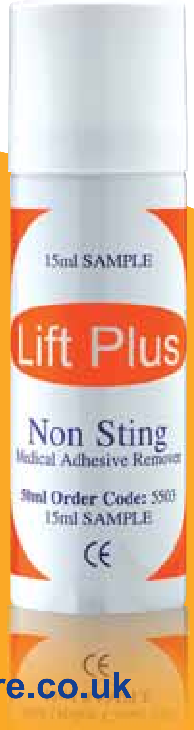
When you feel the time is right for you to start exercising, I am happy to talk to you in person via email or phone. I can be contacted via the Colostomy Association on: 0118 939 1537. I am also happy to talk to any fitness professional that wants to know more about exercise and stomas. Whatever you want to try, keep to a few simple rules, but most of all enjoy!

Bronwen Lowy

Check with your GP or SCN before you commence any exercise programme.

- Start slowly
- Go at your own pace and listen to your body
- Stop when you've had enough.
- Enjoy the experience!
- Don't feel intimidated.

Please remember to always ensure that you have checked with your medical practioner before you commence any type of sport or physical activity.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‘X marked the spot’ and I was off to surgery...

Lisa shares her experiences of colostomy reversal and bowel resection

Lisa Tubbs - getting back on track

At twenty-six I didn’t know what a colostomy was! I didn’t even realise young people had colostomies as I associated them with older people. I quickly found out I was wrong...

I have suffered from severe Endometriosis for years and was having yet another Laparoscopy to laser off the adhesions attached around my ovaries, bowel, rectum, kidneys and other infected areas. Endometriosis is a condition in women where cells that usually line the womb are found elsewhere in the body, these cells behave in the same way as those that line the womb, so every month they grow during the menstrual cycle and then shed blood. This internal bleeding, unlike a period, has no way of leaving the body and leads to inflammation, pain, and the formation of scar tissue (adhesions). There is no cure and the only way these adhesions can be removed is by laser.

A week after my routine operation all was not well and I was rushed in for an emergency colostomy because a fistula had formed. The doctors formed a temporary stoma to allow time for my bowel to heal on it’s own as they wanted to prevent having to perform a bowel resection. Although I was informed before the Laparoscopy that there might be a 2% chance I could end up with a colostomy bag (because there was so much endometriosis around my bowel and rectum) ever the optimist and being squeamish I didn’t research into it. Not knowing was probably better in hindsight. Even before the emergency operation I refused to look at any pictures of people with colostomy bags or read about how they worked as I knew I would find it easier to cope looking at it on my own body. They marked my tummy with an ‘X marks the spot’ and I was off to surgery.

I came round still in denial and not wanting to look under the covers. The nurses were amazing and very supportive which helped me get over the fear. I really felt their empathy which made me feel better and not ridiculous for overreacting. With the best support from my friends and family, I started to deal with it. It was scary to say the least, but you quickly adapt to things thrown your way and realise you can’t always prevent things happening to you.

Crying every time I passed wind in front of people was a regular occurrence during the early days. The lack of control was very embarrassing especially being female and very prudish about flatulence. After years of being discrete and private, it was out there for all to hear!

But as time went on, surprisingly I grew quite attached to my stoma. Knowing that it was going to be temporary definitely made it easier to deal with. I wouldn’t have been so strong if it was a permanent stoma.

It’s very hard for anyone at any age but initially I definitely found it difficult to cope with being young, single and having an active social life. I got braver as time went on and started going out again. I quickly learnt the hard way that drinking too much had a bad reaction in the morning but I adapted by trying other drinks with less fizz.

Buying a new wardrobe to hide the bag was my treat to myself as it helped with my confidence and body image. No one ever guessed I had a colostomy bag as they are quite discreet and by adapting my clothing and wearing magic pants I helped hide it and hold it in.

After six months I had a barium enema to see if the fistula had healed on it’s own. I was very anxious before the examination because everything hung on the results. If it had healed on it’s own I would have a simple reconnection of my bowel and the colostomy removed. Unfortunately it hadn’t, so I went in for a reversal operation of the colostomy bag and the removal of a large part of my bowel and rectum.

Having a bowel resection is a major operation and recovery is longer but emotionally it is easier to deal with. Coming round from the operation I was in such a daze as it was a lengthy operation. I was very weak and it took me a lot longer to regain my energy and bounce back from it. I was in hospital for a week after the operation as you have to be able to have a bowel movement to confirm that the operation has been successful. (I had a small colectomy at the end of the colon where it joins the rectum (part of the sigmoid colon). That first bowel movement was a massive relief and the entire four bed ward celebrated!

During the first few months you can experience going to the toilet up to fifteen times a day, sometimes with urgency and soreness. Unfortunately the frequency is very different to what you may have previously experienced and after about two years it evens out and your body settles down to what now feels normal. You spend a lot of time in the bathroom so taking up Sudoku or reading passes the time!

Initially after the reversal I missed my colostomy bag as I had become comfortable with using it and I was scared about going to the toilet in the normal way again. Because half of my rectum was removed it got confused, my brain had to re-educate the rectum when I needed go to the toilet because it wasn’t compacting the stools. There is a continual sensation of urgency which you have to train your mind to ignore. It took time, and it never goes back completely to how it was before the operations but it’s manageable. Going five or six times a day seems normal now.

From keeping my colostomy a tight secret whilst I had the bag I was more open about discussing it afterwards as I was proud of what I had gone through and felt stronger for it. Those that were aware of the bag whilst I had it were understanding and in many cases quite curious and wanted to know more out of genuine interest.

I work in a Design Agency in London and have done the whole way through my journey. Now, a year and a half on I am ready to start getting on with my career as it was on hold for quite some time as you have to put your health first and make yourself feel good.

There were many funny, embarrassing and cringing moments throughout the six months when I had my colostomy bag but you have to try to see the funny side of these things and laugh!

Lisa attended the recent Induction Days and is now a volunteer for CA...

Department of Health consultations

For new readers to Tidings it is probably worth giving some background to the Department of Health (DoH) Consultations and how we have got to this current position.

The first Consultation impacting on the supply of stoma products was published back in October 2005 and was meant to review the way that products were delivered to patients and how much companies would be reimbursed for providing both the products and the services. At the same time one of the key aims of the consultation was 'to maintain and where applicable improve the current quality of care to patients'. It was evident, from reading the Consultation proposals, that quality of care to patients would be adversely impacted if reimbursement to companies was going to be reduced.

Working closely with other Patient Associations, including the Ileostomy Association and the Urostomy Association, we have provided responses to the initial Consultation and the further five that followed taking us up to the end of 2007. Consultation 6, which closed in December 2007, made proposals which would have meant a reduction in reimbursement to manufacturing companies of approx £25m. Our response flagged, yet again, that if companies were forced to make these savings then patients would be impacted by a reduced product range, reduced funding for research and development of new products, potential reduction in sponsorship for nursing positions etc.

During the early part of 2008 the DoH held a number of meetings with interested parties (companies, nursing groups, patient associations etc) in an attempt to fully understand everybodies concerns and to draw the Consultations to a close. Following these meetings a final Consultation was published in June with a closing date of 9th September. By the time you read this edition of Tidings our response will have been submitted along with those from the other Patient Associations.

In terms of the proposals within this latest Consultation, I can confirm that the DoH have listened to the concerns raised by patient groups and understand the implications for patients. The proposals will still mean a reduction in the reimbursement to companies (now £5m compared to £25m in the previous proposals) and we await with interest the steps that companies will take to make these savings. From my understanding the majority of companies are accepting of these proposals and can now move forward after spending 3 years reviewing the DoH Consultations.

A summary of responses to the Consultations will appear on the DoH website in due course and, hopefully, we should be able to report the end to these reviews in our Winter Tidings.

Scotland- As the DoH Consultations in England draw to an end we are gearing ourselves up for a Consultation in Scotland.

A number of changes are already in place in Scotland regarding the range of companies who are able to supply products to Hospitals and we would be grateful to hear any feedback on this that any of our Scottish readers may like to provide to us. The process at present is somewhat confusing in that patients may only have access to the products of three or four companies whilst in hospital but then should be given a wider choice once they return to the community. These processes have been put in place without any consultation with patients and thought of the impact that they may have.

I was invited to attend a meeting with Shona Robinson MSP back in August along with Anne Demmick from the Ileostomy Association and Hazel Pixley from the Urostomy Association where we were able to express our concerns over the issues raised by the changes. We were pleased at being given this opportunity and happy with the assurances which Shona was able to give us.

We are now awaiting a draft report on the work of the Stoma Care Review Group following which a draft Consultation paper will be produced for us to comment on prior to publication. It is hopeful the Consultation will be published by the end of the year.

As always we will keep you updated on developments and if you have any specific concerns regarding the position in Scotland please let me know by writing to me at Head Office.

Ray Goddard
Office Manager, Trustee and Treasurer

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Dear Nurse...

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

Q: It is twelve months since I was diagnosed with colon cancer. A colonoscopy revealed two cancerous polyps one at either end of the colon. I had an operation to remove both polyps and rejoin the colon. Laparotomy number one.

Due to complications I had three more major and five minor operations over a five month period resulting in a total of four laparotomies the last one being in late October 2007.

I had further problems at the site of the drain at the lower end of the laparotomy scar resulting in three abscesses and the need to have it drained daily via a gauze wick over a period of three months. Since then I have regained most of my strength and put some weight back on but I still suffer discomfort along the scar of the laparotomy particularly at the lower end where I had problems with abscesses. There is a lot of scar tissue which is fine when I am sitting or lying down but when I stand up there is a feeling of tightness and heaviness as if there was a rope beneath the skin. This is helped when I wear a support belt. Is there anything I can do to improve the feeling around the scar in the way of exercise or creams or will it improve in time.

The surgeon now wants to perform a reversal via yet another laparotomy. You will appreciate how I feel about this and despite reading articles on the web and in Tidings I just don’t know what to do. I manage my colostomy well and apart from the occasional day when I think I could do without it, it doesn’t bother me and is just part of my daily routine.
I am 58 years old I didn’t require chemotherapy or radiotherapy and the cancer was stage 2 and had not spread. I have an end colostomy.

Your help and advice would be greatly appreciated.

A: The discomfort you are describing could be due to a tight band of scar tissue, especially as you have had several laparotomies along the same scar. There are no creams or lotions available to resolve this although it may improve over a period of time. If the Consultant is discussing reversal and this requires opening of the same laparotomy scar it may be worth discussing this feeling you have as he may be able to remove the tight band of tissue if this is the cause of the problems. Even if you eventually decide against having the reversal it would be beneficial to talk to the surgeon to discuss your concerns and this feeling of a tight ‘rope’ along the scar.

Q: My Mum who's 57 years old had a colostomy operation since September 2000. Now during the last two months she's suffering from lots of gas. She been avoiding all types of foods that may cause gas, she's been taking all medecines concerning with gas problem. But still it's not stopping.She lost lots of weight. She so desperate you know. She doesn't even know what to eat or take to stop that gas. Do you think is there anything wrong with the colostomy now? Is there any test she can do to know the problem. Please help me with your advice if you can.

A: You do not say if your mum is having any other symptoms such as vomiting or abdominal pain so it is difficult to say if there is a problem with the stoma itself. If it only a ‘wind’ problem then it may be useful for your mum to speak to either her Stoma Care Nurse regarding her diet or even a Dietician. Certain foods do cause excess wind for ostomates and this varies with each individual. It may be useful for your mum to keep a food diary for a period of time and to note when the excess wind is a problem. She may then be able to link it to certain foods. Also you state that your mum has been taking some medication for the wind but you do not say what this is. Some patients find things such as Peppermint (mints, water or tea), fennel (mints, as a vegetable or tea) and charcoal (tablets or biscuits). If your mum does have any other symptoms then it may be useful to speak to her GP or Consultant Surgeon.

Q: My name is Karen Jones, and I have a Colostomy, I have had it for nearly three years, and have to put up with a very large peristomal hernia. I have been seeing a surgeon who says I should loose 3 stone, I have lost a little, but I have had a bad few months I looked after my dad for 3 years and he died in March, I am now looking after my mum who is living with us, so I am finding it very hard to loose the weight. I am scared to see the Surgeon in November, because I have not lost the weight. I do not know whether to cancel him and live with it. My Colostomy was formed because I had very large babies, I had two, the last one was ripped out so because of this she wrecked my bowel. Had three opps to repair sphincter muscle, but did not work, and I began to feel like a old lady. Im age nearly 51.

A: I’m sorry to hear about your parents and the difficult situation you find yourself in. I am sure if you are trying to loose weight and have managed to reduce the weight, even by a small amount, the surgeon will understand, especially if you explain the difficulties you are having. If he is still unsure about operating on you it may be beneficial to see your Stoma Care Nurse to arrange to be measured for an abdominal support. This will help to support the hernia you have and therefore make you more comfortable and will also help to prevent the parastomal hernia getting worse. Persevere with trying to l

Q: I was particularly interested in the article about Abdomino Perineal Excision of Rectum (APER) in the previous issue.
I had this operation 16 months ago, but never knew exactly the name for it.

I have and still do have the discomfort mentioned which was a bit disconcerting to start with as I had started swimming and thought this was to blame, so it is nice to know it is not unusual.

I do still have a discharge from the wound although slight and apparently the opening is down to just a pin prick according to my husband. When I last saw the consultant in March and said it wasn't completely healed he made no comment, so this has made me wonder if it is permanent.

I just wondered if you had any comment on this.

A: You appear to be doing very well following your surgery and hopefully the recent article re-assured you that you are not alone. The discomfort you are experiencing is a common complaint for people following this type of surgery as was suggested in the article. As far as the discharge is concerned you do not appear to be having a major problem and hopefully this discharge will continue to decrease over time. If this becomes of concern to yourself you may want to discuss it further with the surgeon, who may be able to investigate it further.

Dear Nurse...

Please send your medical questions or queries about stoma management to

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

or e-mail
cass@colostomyassociation.org.uk

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

Caring...
"the concern, empathy, and consideration for the needs and values of others."

What do we mean by a carer?

A carer is someone who looks after a relative, partner, child, friend or neighbour who cannot manage alone because of illness, disability or the effects of old age. The person being looked after may live with the carer, in their own home, or elsewhere such as residential or nursing care, sheltered accommodation or a supported living scheme.

In the UK, everyday, six thousand people take on a caring responsibility. The term 'carer' is used to distinguish those who provide care for others on an unpaid basis, from those who are paid (for example; care workers, home helps and people employed by someone with a disability).

For people who take on the mantle of 'carer', whether its part time or 24/7, the emotional pressures are great. The parties involved, 'the care giver', 'the patient or loved one', other family members and friends are all affected one way or another, for some it's a positive experience, for others it may be too much.

Carers are often unprepared for what may become a full time job – mentally, as well as physically, it can occupy your whole being and take you on an emotional roller coaster. Whilst you know you must look after yourself, it is difficult to strike a balance when caring for someone dear to you. If you are working or have some free time - you still find yourself wondering things like, 'Will they see the registrar today?', 'When is the next appointment?' will the 'stoma nurse call?', all those questions and more pop into your head.

Journeying together - a carers experience

In 2000, I journeyed with my mother through all aspects of her medical care and aftercare. Together, we experienced doctors' and hospital appointments, diagnosis and examinations, meetings with medical professionals, outside agencies and more.

After a series of tests and treatments, a blood test showed that she was extremely anaemic; Mum was rushed in to hospital as an emergency. After more investigations to find out the cause of her anaemia, her medical team revealed to me that she had a large cancerous tumour in her bowel. I was shocked but it was now up to me to break the news, she was 80 – 'how do you tell your mother she has bowel cancer?' It was really hard to do, but I did it, she seemed to take it well, although, I knew from her reaction, she hadn't really taken it on board.

I met with her consultants, who were extremely honest and frank, I was told that my mother needed to have an operation; they suggested that it may be possible to take out the cancerous section and rejoin the bowel, this sounded hopeful, but because of her age and other factors, she had a 50-50 chance of survival. The consultants asked me to explain everything to her, and to do it in a positive manor, which I did. It was up to my mother to decide whether to go ahead with the operation, we talked it out, although, I knew what her survival chances were, I didn't reveal them to her or other family members, in hindsight I think that was the right decision.

The operation went ahead, it took hours, the waiting was the worst thing and the not knowing, I spent the time pacing up and down a small family room, would she survive? Finally, she was out and in intensive care and I could see her. She was still heavily sedated with tubes coming from all kinds of places. I remained with her all night, with brief exits to make phone calls to family and friends. I was told later that they could not reconnect the bowel and that the operation resulted in her having a colostomy. She was alive, her daughter had somehow selfishly got her Mum back!

Mum was a 'survivor', but then I had always known that, she had survived the bombing in London during the 'Blitz' and was one of the lucky ones then, but it wasn't luck that had saved her this time it was professionalism and highly skilled medical care! Now the emphasis of our journey changed, it was all about recovery, diet and fitness, care and management of her stoma and confidence building. There was so much to think about, we were still coming to terms with the operation!

Although I was working, I visited Mum, twice a day in the early days, to make sure I could speak to staff and consultants managing her care, it was gruelling, but you find the energy from somewhere!

Mum a born ‘survivor’

Later it became once a day, mainly the evening, but I found this a bit frustrating as I didn’t really know what had happened during the day. “Who she had seen”, “What had been said”, “How she was doing”, Mum wasn’t really able to tell me very much, as she was still very poorly and also hard of hearing which seemed to complicate matters further. So, I decided I would go to the nurse’s station for an update from the registrar or sister on duty every evening, this proved to be the best thing as staff were always very supportive and helpful.

I became my Mum’s personal liaison officer, I found myself in the middle of everything, talking with staff at the hospital, her GP, social services, other patients and their relatives, updating my family and relatives, updating Mum’s friends, arranging when they could visit – it was a whirlwind of activity and it took me by storm! My own young family and my husband though very supportive and extremely helpful, were doing there bit at home without me, trying to keep things on a normal footing – I became torn between my Mother, my family and my work responsibilities, somehow I knew I had to see it through, after all this person had given me life and had taken care of me – I felt I had a duty to her and could not be swayed, its hard to describe the feeling but it just takes over your whole being, I suppose the only word to describe it is ‘love’.

I had discussions with her medical team and social services to try to work out a ‘care plan’ to make sure when she did come home everything was in place. As Mum was elderly, she was assessed to make sure she could do certain daily tasks before she was allowed home from hospital. Her home environment was also assessed. Aids were fitted such as handrails, raised toilet seat, a special type of mattress to prevent pressure sores and a walking frame to aid her mobility. When she did come home there were visits from stoma care nurses, her GP, community nurses, prescriptions to organise, benefits to sort out, shopping, well wishers, family, her home seemed like Piccadilly Circus! When the welcoming party quietened down, Mum and I felt a little disorientated, a home environment is very different to a hospital environment, it was very quiet. Mum had been in hospital for a long time and thinking about it so had I. When you are in hospital everything is done like clockwork, you are up at a certain time, staff come and see you, you have to go for scans or x-rays, others are going about their duties, food is provided, people surround you, you get answers to your questions, there is a social hubbub of activity.

But, we were now on our own, I found myself with no one to refer to and no information about how to care for a stoma or how to change a colostomy bag.

The stoma nurses in the hospital had shown Mum how to take care of her stoma and apply and change the colostomy bag, but because I had been working I hadn’t been there to see it for myself, so I didn’t know anything, I thought Mum did. How wrong I was, I asked Mum to tell me how to do it, but she wasn’t able to. She just kept saying she didn’t want this thing and could I take it away. I felt helpless. She said “This isn’t me, I have always kept myself clean”, “I’ve always looked after myself, this just isn’t me”, “Please take it away, get it off me”: it took a great deal of time and patience to explain why I couldn’t. I learnt to change her bag myself through trial and error, to use the templates provided with her supplies but I wasn’t sure if I was doing it right, but we muddled through together. The biggest problem seemed to be the skin surrounding the stoma, it often looked sore and red, I didn’t know whether this was normal or not. I didn’t know anything!

I know now that she was in denial, she was ashamed of her body and its new appearance, she had always been very meticulous about her body and now she was finding this whole thing difficult to come to terms with.

I found caring for my Mum, bringing up a family and working all at the same time difficult and exhausting. Although, Mum didn’t live far away I would go every morning to change her bag, and make sure she was set up for the day, the same applied in the evening, sometimes I would get a desperate call from her during the day asking me to come over and ‘deal’ with her colostomy bag. She didn’t want to change it herself. I had to stop everything and go! I needed help!

After discussion with her GP and social services and various form filling exercises I managed to secure help, it was part-time help but it was better than no help! I was lucky, the ‘carer’ who was allocated to Mum had stoma experience, and it turned out that her daughter had had a colostomy from a little girl, so she was very knowledgeable. I was very grateful; I learnt so much from her and owe her a great deal of thanks.
Sadly, Mum never came to terms with her colostomy or the management of it, I often felt it was mine and I think she did too! Mum lived for four more years and that time was extra special to us, we laughed as well as cried but we got through!

If I had known about the Colostomy Association in 2000, I would definitely have contacted them for information, support and advice. Although, I do not have a colostomy, I do have a great understanding and empathy with those who do. My experience has left me with a desire to provide carers and patients with information that is clear and easy to understand as well as empathetic to their emotional needs.

Jane
Editor - Tidings Magazine

The emotional dynamics of caring for someone and continuing your own daily activities may be difficult and in some cases utterly impossible to deal with, it really does depend on the support you have around you.

It is often difficult to identify other areas of help and support, as you can become so engrossed in the caring process – and ‘carers’ may find themselves isolated and lost. Ask your GP for help, talk to medical professionals, in hospital or in the community, if you require help - they will put you in touch with patient associations and support groups or if you have internet access there are a number of carer associations you can contact who will be only to pleased to help. If you are a carer of a new colostomate or an experienced colostomate and find you need extra help and advice, contact the Colostomy Association for specific advice on stoma related issues. Remember - don’t ever be afraid to ask for help.

Even when your family member, partner or friend returns home after their treatment or operation, the atmosphere may feel different for a short while. New challenges may have to be met by all, some difficult, some unexpected. People may react differently to their treatment or medical experiences, and those who are ‘carers’ may not recognise their partner, family member or friend as being quite their old self. Time, patience and understanding will help to reassure the person you care about begin to come to terms with themselves and their experiences, don’t forget your input really does makes a difference!

For those of you who read Tidings who are ‘carers’ or ‘former carers’ we would like to hear from you – tell us your experiences and stories.

Carers Questionnaire

We are trying to find out how information is obtained by carers of ostomates, where it is comes from and how useful it is. As a carer, your views are very important to us. Your responses will help us to improve our information and help identify where it should be placed. The information gathered will also help us write a future feature in Tidings and a carers' action plan. Thank you for completing this questionnaire.

1. As a carer did you understand the medical advice offered to your partner/family member/friend about procedures or ongoing care?

Yes ☐ No ☐

If No, please explain:

2. As a carer were you supported and recognised as a key person by GP/Medical Professionals/Consultant/Other?

Yes ☐ No ☐

If No, please explain:

3. Were you and your partner/family member/friend given any helpful literature before and/or after procedures/ongoing care or after care?

Yes ☐ No ☐

If No, please explain:

4. What information would have had made a difference to you as a carer?
Please give details:

5. If you work, does your employer understand and support you with your caring commitment, if so how do they help you?
Please give details:

6. Were you given any information by GP/Medical Professionals/Government agencies or other helpful organisations to help you with your role as a carer?

Yes ☐ No ☐

If Yes, please explain:

7. Do you know what benefits and financial assistance you may be entitled to as a carer?

Yes ☐ No ☐

8. As a carer were you given any information on patient associations, support groups or online support communities?

Yes ☐ No ☐

If Yes, please explain:

9. As a carer where did you find helpful information? (Tick all that apply)

Voluntary organisations ☐ GP surgery ☐
Health professional ☐ Social Services ☐
Carers centre ☐ Library ☐ Internet ☐

Other: (Please comment):

10. As a carer what kinds of information listed below would you find useful? (Tick all that apply)

Benefits ☐ Coping strategies ☐
Medical ☐ Health issues ☐
Financial & legal ☐ Child Care ☐
Rights for carers ☐ Short breaks ☐
Home care ☐ Support groups ☐
Employment matters ☐

Other: (Please comment):

11. In which public places do you think information for carers should be available? (Tick all that apply)

Supermarkets ☐ Post offices ☐Banks☐
Bus stops ☐ Library ☐ Schools ☐
Other: (Please comment):

12. Does your culture, religion, and the way you communicate or any other areas of your life affect your needs as a carer?

Yes ☐ No ☐

If Yes, please explain:

Background information about you – optional

Are you
Male ☐ or Female ☐

How old are you?
Under 18 years ☐ 18-34 yrs ☐ 35-44yrs
45-54yrs ☐55-64yrs ☐Over 65 yrs☐

Are you the main carer for your family member/partner/friend?
Yes ☐ No ☐

How long have you been caring for your family member/partner/friend?

0-3yrs ☐ 4-7yrs ☐ 8-11yrs ☐ 12-15yrs ☐
16yrs+ ☐

This questionnaire is anonymous and all information given is treated in the strictest confidence. Finally, if you would like to make further comments or suggestions please send them with this Questionnaire by post to the following address:-

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

Organisations and charities for Carers - providing support and advice

Carers UK (formerly Carers National Association)
Carers UK provides carers, those supporting them and others with national and local information about benefits they are entitled to.

20 Great Dover Street London SE1 4LX
Phone numbers:
Carers line: 0808 808 7777
Office: 020 7378 4999
Fax: 020 7378 9781
Email: info@carersuk.org
Website: www.carersuk.org
Opening Hours:
Wednesday and Thursday 10.00 am to 12.00 pm and 2.00 pm to 4.00 pm

Citizens Advice Bureau
The Citizens Advice Bureau (CAB) has a network of advice centres across the UK.

Myddelton House
115-123 Pentonville Road London N1 9LZ
Phone: 020 7833 2181 (Admin office only)
Fax: 020 7833 4371 (Admin only)
Website: www.adviceguide.org.uk

Crossroads - Caring for Carers
Crossroads provides practical help and support where it is most needed - usually in the home - through trained Carer Support Workers.

10 Regent Place Rugby Warwickshire CV21 2PN
Phone: 08454 500 350
Fax: 01788 565 498
Website: www.crossroads.org.uk

Directgov
Caring for Someone
Website: www.direct.gov.uk/en/CaringForSomeone

Patient UK
Patient UK was first launched in 1997 by PiP (Patient Information Publications). Aim - to be a reliable and comprehensive source of health and disease information, mainly aimed at the UK general public, but of interest to all.

Website: www.patient.co.uk

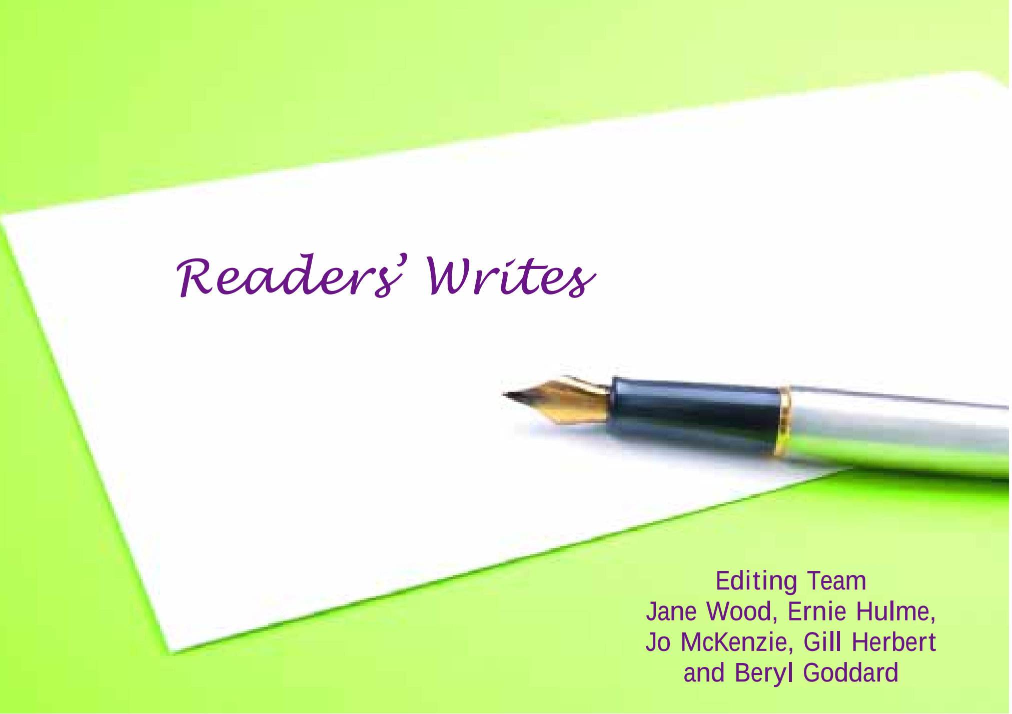
The Princess Royal Trust for Carers
Provides advice and support services to carers of all ages in the UK through a network of independently managed Carers Centres, young carers services and interactive websites.

London Office:
142 Minories London EC3N 1LB
Phone: 020 7480 7788
Fax: 020 7481 4729
Email: info@carers.org
Website: www.carers.org

Young Carers Net
Young Carers Net supports carers under the age of 18 who are looking after someone who has an illness, a disability, a mental health problem or a substance misuse problem.

London Office:
142 Minories London EC3N 1LB
Phone: 020 7480 7788
Fax: 020 7481 4729
Email: youngcarers@carers.org
Website: www.youngcarers.net

Readers' Writes



Editing Team
Jane Wood, Ernie Hulme,
Jo McKenzie, Gill Herbert
and Beryl Goddard

Dear Editor

I started irrigating a year ago and wish I'd known about it earlier. What bliss to know that there is no changing bags after an early morning session in the bathroom. Gosh, have I got through some books during my sittings! The best tip I got from Tidings was to take a chair into the bathroom and face the loo. I did find a wooden seat somewhat hard after about five minutes!

Obviously there have been a few mishaps, but fortunately at home, except for having to forego a coach trip to Highgrove when I had a disaster just before getting on the coach. I had to dash across the road to the school and waved goodbye to friends before walking a mile home to clean myself up. The only relief was that it happened before getting on the coach and not whilst on it. I still go cold at that thought. Hey ho! – life's like that.

Kind Regards
J.T.

Dear Editor

My husband (91) had two major operations in February this year for bowel cancer. We had no idea of the following complications. If I'd have been alerted about the Colostomy Association I would have been spared so much anxiety. He has now got quite a large hernia and has just obtained a girdle. We were totally unaware of this support till we read your magazine rectal discharge explained through your magazine.

What a pity colostomates and carers are not introduced before facing these complications.

Knowing that these changes mean a new way of life to so many people it gives one fresh hope to accept and learn to cope.

Yours sincerely
Mrs C. A.

Dear Editor

I was born on the 27th August 1959. Straight away I was taken to intensive care where I was operated on for a stoma (colostomy) I was born with an inperferated anus and curvature of the spine. I had to be bandaged up all the time as they didn't do colostomy bags for babies. I had the colostomy on the right side and then they changed it to the left side. My mum cannot remember why she can only think because I didn't have room for it as I only have one kidney. I didn't attend school as much because I had to wear nappies and I was in and out of hospital a lot, I also remember I had to have enemas. I remember I used to cry as my mum had difficulty getting it right. There is a lot I could say but its something I had to live with, I'm very happily married and having a very good life.

I couldn't have children but I have a stepson with Downs Syndrome who is a joy to be with.

Yours sincerely
P. K.

Dear Editor

I have found your Tidings magazine very useful and informative over the past year or so. Your article on irrigation was very beneficial.

I am now a complete convert to irrigation and cannot understand why more people do not use this method of coping with the problem. Life is less problematic and the anxiety as to the location of disabled loos etc. is no longer a daily problem. Not to mention less use of valuable NHS money in the supply of bags!

Yours sincerely
Mrs M.S.

Dear Editor

After my bowel cancer operation I was regularly changing my pouch twice a day, and the skin around my stoma became quite red and sore. I found the answer in using a two piece system instead of a one piece. Whereby the backing plate on your skin is only changed two or three times a week the pouch is changed as often as required. I have found the braun system superior, as it is soft, flexible and the two pieces slot easily into one another and stick well.

Do try it, and see if it improves life for you.

Yours faithfully
P. K.

Dear Editor

I received tidings magazine summer 2008 issue 10 today. I always look forward to receiving it; it's been very helpful and comforting to me.

In this issue you have written about Abdomino Perineal excision of the rectum. I had this operation in March 1999, I am still experiencing severe pain when I walk or sit, lying down does help but the pain never goes away completely.

The first five years after my operation I consider to be the most painful years of my life, never ending pain. I was told after a few months things would improve once everything had started to heal and settle down, this did not happen. Three months after the operation I could feel a lump in my bottom, it has never gone away it remains there 24 hours a day.

The consultant I had then did not want to know or help me in anyway, all he kept saying was he could not feel a 'lump' in my bottom although other doctors that came out to me in the early hours of the morning to give me painkillers said they could feel a lump and I should see my consultant to get help.

It was only after speaking to my own dotor and telling him I would not be seeing my consultant again, he wrote to another consultant and it was agreed I should see him. Within a short time he had arranged for me to have a colonoscopy, apparently I should have had one two years after my operation to make sure the cancer had not returned, an MRI scan clearly showed my bowels had dropped down, (been down from the beginning).

The relief I felt finally being told what was causing so much pain I feel is helping me to handle things in a more positive way. I have been told an operation to lift the bowels is no longer being done, it seems the mesh used to bridge the bowel became infected causing patients to die. My stoma has never caused me any problems, I treat it with great respect I have not had to see a stoma care nurse in eight years, had lots of trouble with bags though.

I have thought about writing to Tidings many times about my condition wondering if someone reading the magazine has the same problems as me. I send very best wishes to all colostomate's especially those capable of climbing mountains and riding bicycles, its good to read their stories, I know I could not do those things. I'm 77 years old, I started work when I was fourteen and worked until I was nearly sixty with short breaks to have my children.

I have had a lot of things happen to me in my lifetime but this I'm going through now is sometimes hard to bear, help from the hospital and consultant has been very poor, my own doctor is kind and always there to help. For the last three years I have been taking Gabapentin tablets, after trying many different medications I found these do help.

Thank you once again for your magazine, it always seems to drop through the letter box when I'm feeling low and lifts me up reading about other people and all the other very useful informative reading.

Yours faithfully
A.M.

Dear Editor

In 1957 I attended the outpatient department of Mount Vernon Hospital, Northwood for a year with sickness and upset stomach. This got worse and I was diagnosed as having ulcerative colitis. I was operated upon and had an Ileostomy. At that time I was the ninth patient to have this operation. I was discharged with a thick rubber bag and flange which often leaked. I also had two small boys one six and one four. Luckily I had a wonderful husband who helped at all times. At 90 years of age I am grateful for the wonderful surgery I had all that time ago which has enabled me to enjoy life.

M.C. (Mrs)

Dear Editor and Friends

I have to share this wonderful discovery with you all. If, like myself you have a clinical collection it means you have a bright yellow bag in a bin somewhere hidden from view in your garden. After every change you have to trot outside regardless of rain, wind or snow.

Sometimes, I have guests to stay who are not really aware of my situation and I find myself at a loss as to how to pass by them with my little orange bag without raising eyebrows. 'Well', on TV three weeks ago Mothercare were advertising the brand new Tommee Tippee Nappy Wrapper™ which is a completely odour free system for storing used nappies. I decided to give it a test run - I thought I should let you all know this is an amazing answer to my irritating problem.

You can use it just a couple of times or about twenty times. No odour just a neat little bin in your bathroom. The Nappy Wrapper™ simply locks away smells and germs with a twist. And, it means a lot fewer trips to the outside bin.

The 0.6months cassette given with it (refills too) is perfect. So Mothercare take note you will not only be dealing with new borns but us slightly older colostomates.

Sincerely
K.R. (Mrs)

From Ed...

Dear All...

Thank you for your letters and e-mails - we welcome them all.

Whether you are a new or regular reader of this section you will appreciate the comments and experiences contained within - anyone can contribute and it is essential that YOU KEEP YOUR LETTERS AND E-MAILS COMING as they give help, support and comfort to all who read them.

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

Ed.

In the News...

Prize Winners from CA Conference...

Peak Medical is pleased to announce that the lucky winner of their competition was Mr Young from Gloucestershire who won a Marks and Spencer voucher worth £50. Congratulations from all at Peak Medical. If you require more information about Peak Medical or simply require samples of our products that you may have seen at the Colostomy Association National Conference, then please contact Peak Medical on Freephone 0800 6520424.

Hollister raffle (digital camera):
Prize winner: Mrs Brenda Wade, 32 Viking, Bracknell, Berks, RG12 8UL.

SecuriCare Medical Ltd: The winners of the 2 x £25 cheques from our raffles were:-

Lynda Sergeant Basingstoke RG22 4TE
Chosen Charity: Colostomy Association

Mr. John Clarke Cumran, Gwent NP44 2DU
Chosen Charity: Colostomy Association

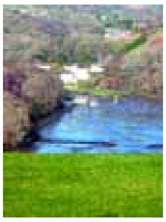
BREAKAWAY Xmas Party at YHA National Forest

Join us on November 15th for the first ever Breakaway Xmas Party at YHA National Forest

£25.95 per person (kids and adults same price) The price includes dinner, the famous Breakaway disco, accommodation, breakfast and any other little surprises we may sneak in typical Breakaway fashion!

To book your place, email break.away@tiscali.co.uk or call Rachel on 0775 1560013

Sorry Breakaway cannot fund any places for the Xmas party. Full payment is required when booking.



Do you feel like a Autumn or Winter BREAK away from it all...

Two properties are available in Cornwall Melyn Goth (sleeps 7+cot) and Gwel an Dowr (sleeps 2) at Polwheveral Mill. The mill is set in a tiny hamlet at the head of Polwheveral Creek one of the most beautiful estuaries on the Helford River - you can explore the stunning cornish countryside and coastline just minutes away.

To book simply contact:
Neil or Sue Hatton
Tel: 01326 3400 58
or email: sue@polwheveral.plus.com

The search is on... for a Celebrity with a Stoma

Many readers will be familiar with the problem which is created for colostomates by the lack of any publicity regarding stomas. The terrifying statistic is that as many as 25% of colostomates consider that life is no longer worth living.

Openness about the condition would largely eliminate such a situation. Breast cancer has surmounted this barrier and it can be talked about openly; bowel cancer is emerging as a topic which it is acceptable to mention, but 'colostomy' is still a word which cannot be used in polite society. I am anxious to change this attitude, and with the presentations of the Great Comebacks Awards scheduled for January 2009, there is a newsworthy item which would justify publicity.

Sky News are interested in helping the CA overcome the media taboo, to illustrate how anyone can live a full life with a stoma, and to give hope to colostomates who feel their lives are effectively at an end. However, news being what it is, the impact would be considerably greater if a celebrity could be found, who was prepared to admit to having a stoma, and say "Yes, I have a stoma. So what?"

If any reader knows of a celebrity who might be prepared to do this, I would appreciate it if they could let me know, without divulging the name, we could then discuss how they might be approached to request their co-operation.

I can be reached by email on adrian.march@orange.fr, and although I live in the south of France I have a special number, 0970 464 280, on which I can be reached at only the cost of a UK local call. Note: this is not a premium rate number! Calls to this number are routed over the internet, and come through to me on my computer, so after 6.00pm is the best time to call. Alternatively, send me a brief email telling me that you will be calling, and when.

Adrian March
Consultant to the Colostomy Association

TOP TIP - Adapting clothing makes life easier...

Joan Hall... shows us how to make skirts easier to wear by attaching her skirt to an underslip.

Feedback... about Tidings from YOU

Dear Editor...
I am writing on behalf of my husband, Howard Jones, to compliment you and your staff on the presentation and contents of the 10th Anniversary celebration issue of Tidings Magazine.

It brought back wonderful memories of the colleagues he worked closely with to produce the first issue of Tidings ten years ago.

Howard and I would like to wish you and the Colostomy Association every good wish for the future and continued success.

Yours sincerely
Ann Jones and Howard Jones

Dear All...
Although my operation was ten years ago, I learned my tips from reading Tidings Magazine. The summer edition - article on Rectal Pain (page 10) will be of great help to many colostomates, including myself.

I hope you will always receive funds to enable the magazine to go on and look forward to reading and learning from future issues.

Thanks very much
Yours sincerely
D.M.T (Mrs)

Dear Editor...
Recently we received 'Tidings' – 10 years on, a most attractive and interesting publication. We are happy to have participated in that first year!

Congratulations to all at CA past and present on your achievement. May you continue to flourish.

With very best wishes to all at the CA office

Kind Regards
Cynthia Robinson
EOS Spain

Marketplace

If you have anything to sell, an event to advertise or a message to communicate, you can place a small-ad for as little as £20. Please contact Ray Goddard at Head Office on 0118 939 1537 for more details. Advertisements received before 21st November 2008 will be considered for inclusion in the next issue of Tidings.

Ostomy Bag Covers by Linda

Covers made to fit any stoma bag. Most colours available. Cotton, lace or silky fabrics.
Also lightweight denim and other prints available.
Most individual requirements can be met.

Telephone:
01205 723327
Linda Butler
(a fellow Ostomate).

Nurses, did you know...?

We can mail out your invitations free of charge to all stoma care patients in your area. Contact CA Head Office for more details.

Tidings

Open Days held by Nursing Professionals

Royal Bournemouth Hospital Stoma Care Open Day
Date: 25th October 2008
Time:10am – 4pm.
Venue: Village Hotel, Wessex Fields, Deansleigh Road, Bournemouth, BH7 7DZ

Aintree Hospitals Open Day Colorectal/Stoma Care
Date: 30th October all
Time: 10am – 3pm
Venue: Princess Royal Suite, Aintree Racecourse, Ormskirk Road, Aintree L9 5AS

Royal Gwent Hospital Patient Coffee Morning
Date: 1st November 2008
Time: 10am – 12pm
Venue: Princess Ballroom, Kings Hotel, 7-8 High Street, Newport

Southern General Hospital Patient Open Day
Date: 1st November 2008
Time: 11am – 2pm
Venue: Walton Conference Centre, Southern General Hospital, Glasgow G52 4TF

Peterborough District Hospital Stoma Care Open Day
Date: 29th November 2008
Time:10am – 1pm
Venue: Cresset Leisure, Rightwell, Bretton Centre, Peterborough PE3 8DX

Stoma Care Open Days are organised by nurses working within the NHS, where several manufacturers and suppliers are represented, (are included on Marketplace free of charge.)

For a complete list of Stoma Care Open Days visit our website:
www.colostomyassociation.org.uk

colostomy association

Reader Offer...

Order your Christmas Cards today...

The husband of one of our volunteers has very kindly painted two watercolours exclusively for us to use as illustrations for our Christmas cards and I am sure that you will agree that they capture the Christmas feeling superbly.

We are pleased to be able to offer these cards for sale to Tidings readers.

Boxed set of 8 Christmas cards (two different designs as shown above) with matching envelopes available at £3.00 per box inclusive of postage and packaging.

How to order: If you would like to order a box/boxes of cards, please complete and return the order form to 'Christmas Cards', Colostomy Association, 2 London Court, East Street, Reading, Berkshire RG1 4QL, or telephone the office on 0118 939 1537.

Order Form: Christmas Cards Offer...

Please forward____box/boxes of Christmas cards at £3.00 per box
I enclose a cheque for £______ made payable to the Colostomy Association inclusive of postage and packaging.

Name: ______________________________
Address: ______________________________
____
____
Postcode: ______________________________

Support Group in the Spotlight

Royal Victoria Infirmary Support Group

I would like take this opportunity to update patients in the Tyneside area. There are three stoma support groups in our locality. We have a lovely little crowd who meet every Friday morning, it's like a friendly social club, where the same people turn up every week to enjoy good company and refreshments. Sometimes, we organise a meeting with a manufacturers representative to talk about products or meet with our resident nurse. We have two meetings held at our local hospital bi-monthly, one is held in the morning 10:00 am -12:00 noon, the other one is held late afternoon 4:00 pm - 6:00pm for patients who may be at work during the day. There are three volunteers who help run the groups with nurses from Newcastle.

If anyone is interested in joining us please call: 0191 2341109 and I will be glad to give them details of times and venues.

CA Contact volunteer - Gordon Weatherburn

Put your group in the Spotlight... Write and tell us about it and we will do our best to include your article and any photographs.

News of local stoma support groups...

The Oops Group:
Julie Morrisroe, the senior stoma care nurse at Guisborough Primary Care Hospital has set up a support group. For more information call Julie on 01287 284113
www.oops-groups.co.uk

MESS (Mid Essex Stoma Support)
Meet in Bromfield every 5-6 weeks.
Next meetings
Friday 24th October - Meeting and Quiz Night, Medical Academic Unit, Broomfield Hospital, Chelmsford
Sunday 16th November - Members Lunch at Writtle College, Chelmsford
Friday 12th December - Annual Christmas Dinner at Writtle College, Chelmsford

For more details contact Clive Blanchard 01245 468750

WBOC (West Berkshire Ostomates Club)
Meets quarterly at Greyfriars Church Centre, Friar Street, Reading. Next meeting 19th November – to include a presentation by David Orton showing beautiful slides set to music. Refreshments provided, all welcome.

"FRIENDS" is an ostomy support group covering East Lincolnshire. We were founded in 2003 with four members and now have over 100 ostomist and carers on our mailing list. We meet monthly on a Tuesday afternoon at Rochford Tower Hall Boston Lincolnshire.

Our next meetings are Tuesday 28 October. A talk by the representative from "SALTS" Tuesday 25 November. A talk by the representative from "Coloplast" For further information please contact either of our joint secretaries.
Mrs Betty Williams
01205 724120
Mrs Sheila Hodgson
01205 364493

Devon IA - Serving Devon and south Somerset

Meeting Friday 31st October 2008 at 12 noon at the Village Hall Monkton Heathfield, Taunton. Guest Speaker Jill Catto. Pre Christmas Meeting Saturday 29th November 2008 at12 noon at the Community Hall, Rydon Road, Kingsteignton, Newton Abbot

Refreshments and company product displays Anyone with a stoma is welcome to attend.

For more information contact Secretary:
Margaret Bond on 01392 44 73 74
E-mail:
Bomarg10@aol.com

Airedale Ostomy Support group - meets 2nd Thursday every month at 7pm in the Day Hospital for the elderly in Airedale Hospital.
A stoma open day/exhibition will be held on December 2nd at Skipton Town Hall 11am – 3pm hosted by Jean Ross and Lynn Shaw, stoma nurses at Airedale NHS Trust.

The Cornwall Ostomy Support Group
Next meetings dates:
Tues 7th Oct, Tues 4th Nov, Tues 2nd Dec 08. (2-4pm)
Christmas lunch in Carnon Downs Garden Centre 12noon followed by Mince Pies in Hall!

Tribute to Joan West

'Dedicated Contact Volunteer for BCA and CA'

I first met Joan seventeen years ago. Talking to my stoma nurse, she said that she knew a lady looking for a man. Well, what does one say to that! Joan, was already a volunteer for the then BCA looking after the female side of visits, but felt a man would be more suitable for the men. So I agreed to join and after a days induction at Reading, it was all systems go.

From the very start it was obvious Joan was committed and enthusiastic about her role as a visitor. Although disabled, she did not let that interfere with her work in helping and supporting others

During our time together, Joan and I attended many open day road shows. Joan was part of the scene. She knew all the company reps plus volunteers from the ia and ua, but more importantly she was widely known by the vast amount of visitors who attend these events. If she was unable to make it, I knew I would be asked time and time again 'Where's Joan?

The last few years saw an end to Joan's home visiting as sadly her health began to deteriorate, she was unable to walk and relied on wheelchair mobility. Did this stop her attending open days? No way. She thoroughly enjoyed them and continued her supporting role from home via emails and the telephone.

I attended the last three open days without Joan due to her ill health. It made me realise just how much Joan was loved as so many people ask her whereabouts. Unfortunately, Joan never attended another open day and sadly passed away.

To sum up, Joan was a very determined, gutsy lady who would always put others first. Not once did I ever hear her complain about her own severe problems and disabilities. Yes, she spoke her mind but never in a nasty or offensive manner. Joan remained fully committed to the CA in her role of helping and supporting others. Above all she remained cheerful.

It was a great privilege to have known and worked with Joan for all of those years and it seems strange not to have her with me at open days. The CA has lost a very loyal member who will be hard to replace.

Finally, to Joan's daughter Ann, I would say your mum was an admirable lady who dedicated a large part of her life in helping and supporting others. I know you are proud of her and will miss her. Your mum has made a lasting impression not only on me, but on the vast majority of people she came into contact with.
WELL DONE JOAN.

Stephen Bonham
Volunteer Leics/Warks


Appeel
No sting
Medical
Adhesive
Remover
Order Code: 3500
Appeel
No sting
Medical
Adhesive Remover
Order Code 3505

Fundraising...we need your help

‘Tidings’10th Anniversary - Car Raffle

Our main fundraiser this year is the raffle of a brand new Vauxhall Agila Club, which take’s place on November 15th 2008. CA would like to say a HUGE thank you to everyone who bought the tickets enclosed in the last issue of ‘Tidings’.

If you haven’t already bought tickets and would like to, or think you may be able to sell a few books at your local support group, workplace etc. Please contact Head Office on 0118 939 1537 and we will post them to you.

Donations - In Remembrance

In memory of Miss Muriel Betty Mary Ridout - CA was left a legacy for the sum of £1000 in the will of Miss Ridout who passed away in December 2007.

In memory of Mrs Joan A Lamb - Friends and neighbours made a donation to CA of £50 in memory of Mrs Lamb who passed away recently.

In memory of Mr Timothy Allen - CA received a donation of £211 in memory of Mr Allen.

In memory of my Dear Wife - The CA was chosen to receive a donation in lieu of flowers on the sad passing of my dear wife. I have a colostomy, and my grandson has recently become a colostomate at 30.
G.H.

From CA: Thank you to all the above for thinking of CA at a difficult time.

Bowls Scramble at The City of Derry Bowling Club...

A member of our club Mr A. Torrens belongs to your Association, he is highly praiseworthy of the work of the Association and the help that he has received. So much so, that we decided to organise a fundraising event! A bowls scramble was held on the 15th May 2008, funds raised amounted to £300.

From CA: Thank you to all at The City of Derry Bowling Club for your enthusiasm!

‘500 Club’...

As well as raising funds for the CA the 500 club gives members a chance of winning a quarterly cash prize of up to £500.

An added bonus...the December draw will have a further prize of £1000 which will make a fantastic post Christmas present for the lucky winner!

Be part of our exclusive ‘Club’ and Win! Currently, we have nearly 400 members, membership is restricted to the first 500 applicants - so, what’s stopping you why not join the 500 Club today!

Simply call Head Office 0118 939 1537 or email: cass@colostomyassociation.org.uk, for a membership form. (Payment is by standing order, either £24 per year or £12 half yearly)

Tell us more about your fundraising events...for CA

Fundraising is an immensely important source of income for the Colostomy Association...as we rely solely on donations to continue our work of giving support to colostomates.

Visit: www.colostomyassociation.org.uk and click on ‘donate’ to learn more...

SASH

- The Sash belts are available on prescription and suitable for both male and female.
- All belts are custom made from information given on our Order Form and a hole is cut into the belt flange to fit your preferred pouch.
- No fittings are required. Belts are processed and mailed within two working days.
- For further information and to obtain an Order Form Freephone : 0800 389 3111

Security and Leakage Belt

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

“the ring of confidence”

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

Ref. no. SR103

Sash Medical Limited
“Woodhouse”, Woodside Road, Hockley, Essex, SS5 4RU.

Stoma Support and Hernia Belt

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

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

Ref. no. S1

Freephone 0800 389 3111
Website:- www.sashstomabelts.com

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

For more information:
SASH Woodhouse Woodside Road Hockley Essex, SS5 4RU England
Telephone: 0044 (0) 1702 206502 Fax: 0044 (0) 1702 206502 Freephone: 0800 389 3111
E-mail address: info@sashstomabelts.com Website: www.sashstomabelts.com

Campaign for change...

Support the Colostomy Association today

Learn how we make a difference to colostomates and how YOU can help us continue to make that difference

The Colostomy Association

is an independent charity, financed solely on donations. This means that we must seek ongoing support to ensure our important work can continue.

We really can make a difference...

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

How we help colostomates...

The Association continues to help colostomates who are experienced and those who are new to 'living with a colostomy'.

We have a range of advisory literature, written by colostomates and nursing professionals, readily available on request. Plus our quarterly magazine 'Tidings" especially written for colostomates, their families and their carers.

We have over seventy contact volunteers covering the country they are fully trained and experienced volunteers who are colostomates. Our volunteers are dedicated individuals who bring a human touch, to what can sometimes be a delicate and emotional time. Our contact volunteers are often asked to visit patients before their colostomy surgery, and afterwards in hospital, usually at the request of the stoma nurse. Home visits by our contact volunteers can also be arranged by request.

We attend organised stoma care nurses 'open days', where you can come and learn more about your colostomy, in a friendly atmosphere, and discuss any problems. We give these events our full support.

The Colostomy Association also attends manufacturers' and suppliers', open days and exhibitions, keeping you up to date on stoma bags, assessories and services via 'Tidings'.

Importantly, we are involved in ongoing consultations with the National Health Service on your behalf and will keep you informed of issues that may affect you.

Here's how YOU can make a difference to US...

Single or Ongoing Donations...

Single donations from individuals and fundraising events are always welcome and greatly appreciated. Your financial support has never been more important. You can help the Colostomy Association support other Colostomates by making a ongoing donation via standing order-simply fill in the form overleaf or on line at www.colostomyassociation.org.uk

Become a 'Friend'...

We would like to invite anyone with a colostomy, (permanent or temporary) and/or members of their family to become 'Friends of the Association.'

A 'Friend' is asked to make a regular commitment of £12.00 (or more) to the Association each year, either by standing order, cheque or postal order. This will ensure that we are able to continue to produce four issues of Tidings per year - full of the latest news, product information, hints and tips and real-life stories from other colostomates.

This regular payment will ensure that there is always a helping hand for those who need it, now and in the future – including some colostomates yet to be born. There are many thousands of adults and children, who, now and in the years to come, will receive a life saving colostomy.

Donate via Payroll Giving

Payroll giving is a scheme that enables employees to give to any UK charity straight from their gross salary (before tax is deducted), and to receive immediate tax relief of up to £4 for every £10 donated.

To set up a regular gift contact your employer's payroll department. If they do not have a suitable scheme in place they can set one up free of charge, simply by contacting an approved Payroll Giving Agency.

Legacies - a gift in your will

Legacies are an important source of funds for charities. Some of the larger charities, such as Macmillan Cancer Support, receive up to a third of their income from legacies. So, if you are about to make a will, or are considering making a change to your current will, spare a thought for the Colostomy Association and consider making a legacy to help us to continue to support colostomates country wide.

Your donation to the Colostomy Association today...will mean we can continue to reach out to other colostomates their families and their carers with support and encouragement.

colostomy association

I would like to make a single donation or ongoing donation or I would like to become a 'Friend'

☐ I would like to make a single donation. I enclose a cheque/postal order made payable to Colostomy Association Ltd.

☐ I would like to become a 'Friend'. I enclose a cheque/postal order for £12.00 or more, made payable to Colostomy Association Ltd.

☐ I have completed the Standing order form on Page 46 (please complete the standing order form overleaf)

☐ Please tick here if Gift Aid applies to your donation (see overleaf for details)

Please note: Please ensure that we have your full name, address and postal code -thank you

Office Address: 2 London Court, East Street, Reading RG1 4QL Tel: 0118 939 1537 Helpline: 0800 328 4257
E-mail: cass@colostomyassociation.org.uk Web: www.colostomyassociation.org.uk
Registered Office: Mill Cottage Polwheveral Constantine Falmouth Cornwall TR11 5RW Registered Charity No: 1113471

Donations & Standing Order Authority

colostomy association

Please help the Colostomy Association to support other colostomates by making a donation - thank you

Please return this form to: Colostomy Association 2 London Court, East Street, Reading RG1 4QL

Title: First Name: Surname:

Address:

Postcode:

Tel: Email:

Instruction to your Bank/Building Society to pay by Standing Order

To the Manager (Bank or Building Society)

Address:

Postcode:

Name(s) of Account Holder(s)

Account No: Sort Code:

Please pay:

NatWest Market Place Reading Branch
13 Market Place Reading RG1 2EP

Account Name: C.A. Ltd

Account No: 88781909 Sort Code: 60-17-21

The sum of: £

Amount in words:

Date of first payment:

and thereafter on the same day every **week/month/quarter/year** (delete accordingly) until further notice. Please cancel any previous standing order in favour of this beneficiary.

Name: (IN CAPITALS)

Signature: Date:

I would like the tax to be reclaimed on any eligible donations that I have ever made or will make to the Colostomy Association until further notice.

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I confirm that I pay an amount of income tax and/or capital gains tax at least equal to the tax that the Colostomy Association reclaims on my donation in the appropriate year (currently 28p for every £1 donated).

Signed: Date:

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- *Non Sting* • *Rapid Dry Formula*
- *Quick & Easy to use* • *Protects Skin from faecal & urinary effluent, digestive juices & adhesives*
- *Aids in flange/pouch/dressing adhesion & removal*

OstoGuard No sting Barrier Film is a rapid Dry Film specially created from the latest silicone technology and incorporating Lavender Essential oil, the oldest of natures remedies for soothing painful sore skin!

SAMPLE EVALUATION RESULTS

- **92%** said OstoGuard Barrier Film is very effective
- **81%** said OstoGuard Barrier Film improves parastomal skin condition
- **75%** said OstoGuard Barrier Film is better than their current product

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"The product has made a massive impact on my life I was shocked at the difference it made to me and my skin. Did not sting - very soothing"

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Freephone 0800 220 300

Product Code: RMC3
Box 30 x 3ml Sachets

Product Code: RMC4
Single Multi use Dab on Bottle 30ml

Product Code: RMC5
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NAPRAP™ PANT

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Our unique Waterproof Naprap™ Pant looks good and feels great to wear!

Our own design team have developed the pant utilising the specialist breathable and waterproof fabric Naprap'

- *The Naprap pant gives added security for Ostomates*
- *May be used with/without a pad for low to medium urinary incontinence and faecal incontinence.*

	Sizes	Code
Ladies	10-12, 14-16, 18-20, 22-24	LNP
Mens	S, M, L, XL, 2XL	MNP
Price per pair £15		

For more information or to order

Phone 0800 220 300

or go on line at

www.ostomartstore.co.uk

Upfront

Spotlight on 'Rosemary' and grateful thanks.

Rosemary's appointment as editor came at a time when the Trustee's and staff were all working hard to get the fledgling Colostomy Association off the ground.

Tidings being well read by ostomists and healthcare professionals alike and supported by the generosity of our advertisers has always been an invaluable communication tool for the Colostomy Association.

Being an impartial voice we needed to let our readership know that not only did we understand their needs, worries and desires we also knew how they felt as we also shared our life with a stoma.

You get a measure of what Tidings means to our many friends when you read the letters and e-mails sent in to us each and every week.

To some readers Tidings is looked upon as their only form of support and contact with the ostomy world.

Rosemary continued to develop this relationship, and like me you may have noticed that a great number of the articles, letters and suggestions that appeared in Tidings made you feel that you had experienced something very similar.

It is a legacy that our new editor Jane Wood is well familiar with as she has experienced life with a stoma through the difficult and sometimes traumatic eyes of a carer.

It is a difficult task that awaits Jane but she has the support of her editorial team and that of the Trustees to rely on.

Jane is also a consultant to CA and being the senior partner of Art Direct, is the driving force behind the new look of Tidings.

We all know that she will bring us the "fresh ideas" that Rosemary wanted whilst maintaining the essence of our support – empathy.

So our grateful thanks go to Rosemary Brierley who being a glutton for hard work stays on as one of our "out of hours helpline" volunteers and has agreed to be on the list of contributors to Tidings - and a warm welcome to Jane Wood who doesn't yet realise that the insignificant slip of paper she signed for me was actually a ten year contract.

Ernie Hulme
Vice Chairman of Trustees

Get your Support Group Published - If you contact us before 21st November 2008 we will publish the date and venue of your next Stoma Support Group meeting.

Is there no support group in your area? Are YOU interested in setting one up?
If so let us know at head office and we will provide help and advice. We can also put you in touch with other ostomates who have set up their own local groups.

Dedicated to Colostomates and their Carers

Tidings is your Magazine...

Submissions:

If you have a story, article, letter or any other item you would like to appear in Tidings, please send them with any relevant photos or pictures to: The Editor, Colostomy Association, 2 London Court, East Street, Reading, Berkshire RG1 4QL or e-mail: cass@colostomyassociation.org.uk.

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

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

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

If you need assistance please call Jane or Mike on 0118 983 6226

FeedBack...

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

How to contact us...

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

Helpful
Groups & Organisations

Other Ostomy Support Associations...

- IA (The Ileostomy and Internal Pouch Support Group)
  Freephone: 0800 0184 724
  www.the-ia.org.uk
- Urostomy Association
  Tel: 01889 563191
  www.uagbi.org
- IOA International Ostomy Association
  www.ostomyinternational.org
- Gay Ostomates
  Tel: 0844 414 2356
  e-mail info@gayostomates.org
  www.gayostomates.org

Support Organisations for medical conditions...

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

Although Macmillan Cancer Support and Cancerbackup are merging all telephone numbers and websites remain the same at the present time.

- National Association for Colitis and Crohn's disease
  Tel: 0845 130 2233
  www.nacc.org.uk
- The Gut Trust
  (Irritable bowel syndrome)
  Tel: 0114 272 3253
  www.theguttrust.org
- Incontact
  (Incontinence & Diverticular disease)
  Tel: 01536 533233
  Web: www.incontact.org

RADAR
the disability network

NATIONAL KEY SCHEME

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

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

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

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

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