colostomy association

Tidings

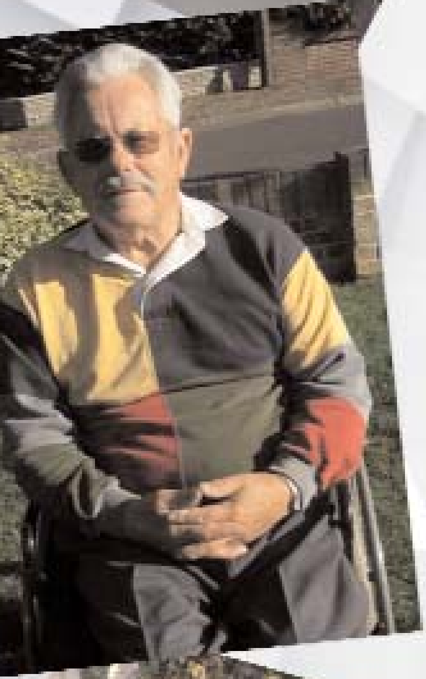
Winter 2007 Issue 8

Dedicated to Colostomates and their Carers

inside...

real people with real stories to tell...

readers share their own personal experiences



plus...

parastomal hernias

hints and tips

and all our regular features...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Tidings
Dedicated to Colostomates and their Carers

The Colostomy Association is a charitable company limited by guarantee (Registered Charity No: 1113471) that represents the interests of Colostomates and other ostomates. We provide support, reassurance and practical information to anyone who has or is about to have a Colostomy.

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inside
this issue of Tidings

Dear Readers..

Something that many people don't realise when they first have a stoma is how many other ostomates there are in this country. It is impossible to come up with a precise figure, but it has been estimated that there are at least 60,000 colostomates and more than 110,000 ostomates in total.

From your letters we know that you like to read about other people: why they needed to have stoma surgery, and how they cope as ostomates. In this issue all those whose photographs appear on the front cover tell their own, very different, stories.

For those readers who didn't manage to attend the Colostomy Association National Meeting in September, we have included summaries of the presentations on parastomal hernias given by a surgeon, and a nurse specialist. These appear in the central eight pages of the magazine along with two colostomate's experiences of coping with a hernia and some suggestions about how new ostomates can reduce their chance of developing a parastomal hernia.

When I began editing Tidings in August 2006, I had been a colostomate for sixteen years. I was very keen to find articles about new topics that would be of interest to people, like myself, who had been reading ostomy magazines for some time. What I forgot was that not only were long-standing ostomates receiving Tidings, but so were those facing a stoma operation or just recovering from it. There needed to be more about the basics of living with a stoma. So in this issue we have a collection of hints and tips for new ostomates and also an article on the different types of stoma appliances available.

As I write this letter Christmas is approaching, but by the time the magazine is mailed out it will be 2008. So I would like to take this opportunity to wish you all a Happy New Year from everyone on the editorial team of Tidings.

Best wishes,

Rosemary

Rosemary Brierley
Editor

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, 15 Station Road, Reading Berkshire RG1 1LG or e-mail them to 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.

Now our family is complete

When I called the helpline to see if there was any information on pregnancy for those of us who have colostomy, I promised to send in a picture of our daughter once she was born. Well things have been a little hectic. It's been harder than I thought being a mum with a disability. I couldn't have coped without the constant support of my husband and my mum, but six months on we are doing really well! Ela (pronounced Ella!) was born on the 13th January 2007 weighing 8lb 2oz!

I've had over twenty operations since I was a baby and I really wanted to do the most natural thing in the world - naturally! I was worried as they initially thought I would have to have a Caesarean section. I would have to be properly anaesthetised as my Spina Bifida would hinder the epidural. However, eventually, the specialist agreed I could try natural childbirth.

I had a great pregnancy, which was unexpected. I felt well and did everything I was suppose to and managed on just Paracetamol! I did get a hernia behind my stoma but this was a small price to pay. We had waited six and half years for Ela, had lost babies during that time and were beginning to come to terms with life without a child. However, my husband, Mark, and I have a fantastic relationship. We are best friends as well as partners and we knew that, although we wanted a child, our life together was happy - then along came Ela! I hardly dared breathe whilst I was pregnant but as the weeks passed I dared to daydream of the day she would be part of our family. When we went to see Robbie Williams I was that worried that the noise would affect her that I sat in my wheelchair at the concert with my huge pillow wrapped around my tummy! - but it was a great night!

The day that I went into labour I was not nervous at all. I had the pool filled up at the hospital and just had gas and air. I was doing so well, then, towards the end, the baby turned to face the wrong way and the scar tissue on my spine swelled against the pressure and she got well and truly lodged! That was agony and I had to go to theatre where she was born by ventouse and I ended up with a lot of stitches! The anaesthetist gave me a big shot of something and I came round to see Mark holding a tiny bundle! I was so disappointed that I'd missed seeing her born but she was safe and so was I.

Cheeky little baby Ela

We now have a very cheeky little one who knows she's adored! My life has taken some unusual turns throughout the last thirty years and having a baby to love was something I didn't think would ever happen to me. It's hard enough looking after myself. I am so lucky to have a wonderful husband and Mum who have been there for me; their support has never wavered. It wasn't until I was a Mum myself that I could really appreciate all that my Mum has been through. I used to think I was the one having a bad deal being in hospital having things done to me but it must have been harrowing for my Mum looking on and feeling helpless. Yet she spurred me on to walk even when at Great Ormond Street they said I wouldn't. She used to buy me an Enid Blyton book every time I successfully catheterised myself at six years old. In fact I have a whole library as I got one after each operation as well!

When I had my colostomy I was twelve years old; it was something I wanted as nothing could be worse than daily enemas and the pain. However, it was still hard to accept especially as my teens were just round the corner, but My Mum got me through it, always making me feel special. I can't imagine how she coped; I truly hope and pray that I never have to do that with my own daughter.

As for my husband, well he makes me feel as though I'm the most beautiful woman in the world and has given me so much confidence. I shall never forget the first time I told him I had a colostomy: I kept saying, 'I've had an op on my tummy that's still there' and he kept saying, 'What kind of op?' Eventually I came out with it and said, 'I've got a colostomy!' I remember cringing with my head down thinking oh well this is the end! He said. 'Oh thank goodness for that! Is that all? I thought you were going to say you had a third arm!' Ten years on and we are still as much in love with each other and now our family is complete!

Well thank you for listening to my story. I really appreciate it. I am still at home with Ela. I haven't gone back to work yet. I do love my job as a Personal Banking Manager at Lloyds TSB but I can't bear to leave her just yet! When I do, it will only be for two days a week! We've just built a bungalow at the bottom of Mum's garden which will really help me physically. It's almost complete but as I'm off work, funding is low, so we'll have to wait a little longer but we are perfectly happy living with Mum and my stepdad, Richard.

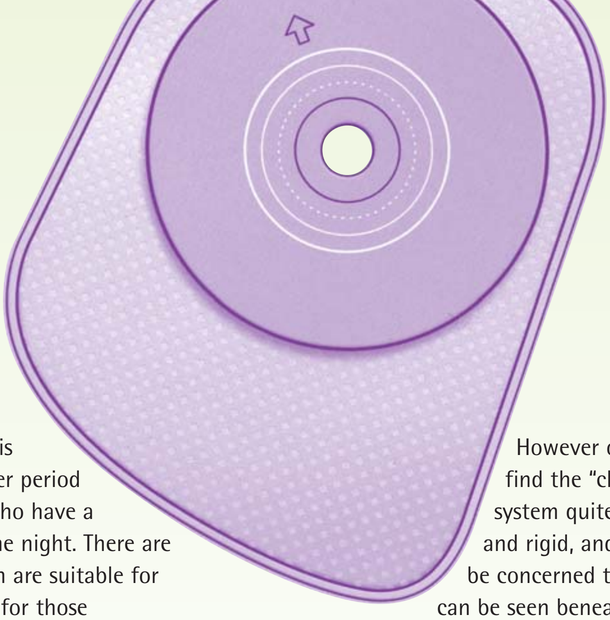
I used to talk to people who were having surgery done as I think as long as you remain high spirited and regain your smile you can get through anything. Life is for living; you've just got to hold on to the courage to get out there and live it!

Best wishes to you all.

Jo Logan
July 2007

> My life has taken some unusual turns throughout the last thirty years and having a baby to love was something I didn't think would ever happen to me... Life is for living; you've just got to hold on to the courage to get out there and live it!

Choosing... the right pouch



After surgery it may be a while before the stoma starts working. When it does it will first of all produce wind and then a fairly liquid output. So on returning from theatre a new ostomate will usually be wearing a post-operative drainable pouch. This will make it is easier to release wind and to empty fluid motions. The pouch may be made of transparent plastic so the nursing staff can check on the stoma. They will want to observe when the stoma begins to work and make sure the join between the skin and the bowel is healing well.

Before you leave hospital the stoma care nurse will select the pouch which is most suitable for you at the time. If you have an ileostomy the output from your stoma will always be fairly liquid and you will be advised to continue with a drainable pouch. If most of your colon was removed when your colostomy was formed the output may also be liquid. Again a drainable pouch may be best. There are many, many different types to choose from so it is not likely to be same as you were wearing when you came back from theatre.

Up until a few years ago almost all drainable pouches closed with a clip. This rigid plastic clip was often uncomfortable to wear and had a habit of getting lost at the most inconvenient moments! Now most drainable pouches have a system which involves rolling up the opening and fastening with Velcro or soft ties. This makes it a lot more comfortable, with no chance of losing the clip. The newest pouches also have an easy-open drainage outlet, which is much easier to keep clean.

If you still have most of your colon intact then after a period of rehabilitation your motions will probably be formed rather than liquid. So your nurse will suggest a closed pouch. Again there are very many to choose from.

Closed pouches come in all shapes and sizes from mini to maxi. Minis have a small capacity for times when you know your stoma is unlikely to be active or for going swimming, while maxis can be worn for longer period of time or by those who have a high output during the night. There are also stoma caps which are suitable for intimate moments or for those colostomates who irrigate.

If you have concerns about disposing of used pouches your stoma care nurse may suggest a toilet-flushable version. This has an outer pouch and an inner liner. When it needs changing the outer pouch, which is unsoiled, is removed and can go in the bin. The inner liner contains the motion and is flushed down the toilet. At present only one manufacturer produces this type of pouch. Many people may feel this is ideal for them but there are others for whom it is not suitable.

Both drainable and closed pouches can be one-piece or two-piece. In a one-piece pouch the flange (the pad of adhesive which sticks to the skin) comes already attached to the pouch. In a two-piece system the flange, or base plate, is separate: it can remain in place around the stoma for two to four days. Used pouches can be removed and replaced as required. The advantage of this is that the skin remains undisturbed whereas frequent removal of a one-piece system can lead to sore skin.

In the past most two-piece pouches clipped to the base plate with a circular "Tupperware-like" seal. Some ostomates may find it difficult to position the flange correctly around the stoma. They can find it easier to use this type of system because a carer can help to fit the base plate correctly. Then the pouch can be changed as required without assistance because it is possible to hear and feel when the pouch is securely attached.

However others find the "clip-on" system quite bulky and rigid, and may be concerned that it can be seen beneath tight clothing. This has led to the development of coupling systems which rely on adhesive. Those with limited hand movement due to arthritis may find it easier to use this two-piece "stick-on" system.

Whether it is a one-piece or a two-piece the most important requirements of a pouch is that the seal around the stoma is secure and the adhesive is skin-friendly. Hydrocolloid has been used for many years to make the familiar yellow flanges and base-plates. All the manufacturers have their own secret recipe and ostomates generally find that one manufacturer's product suits them better than another.

One recent innovation is Microskin, a means of attaching the pouch directly on to the skin with a transparent layer as thin and flexible as "Clingfilm". It follows the contours of the skin so ostomates who have creases or crevices around the stoma may find it helps to prevent leaks.

For those whose stoma is retracted below the surface, or flush with the surface, of the skin there are pouches and flanges with built in convexity to give a good seal. These convex systems should only be used on advice from a stoma care nurse.

Another development is the flange which can be moulded into shape, rather than cut. Those who have irregularly shaped stomas and problems with faeces leaking onto the skin may find this innovation helpful.

Many of the products mentioned above are advertised in Tidings. If you feel one might help, fill in the reply slip or ring the manufacturer for samples. Or you could see a range of stoma appliances firsthand by visiting a stoma care open day.

Remember it is best not to try too many different pouches in a short space of time. Give each one a few days if you think it might help. If it doesn't, go back to your usual product for a while before trying something else. Also if you are trying something new it might be best to do so on a day you're not going out – just in case.

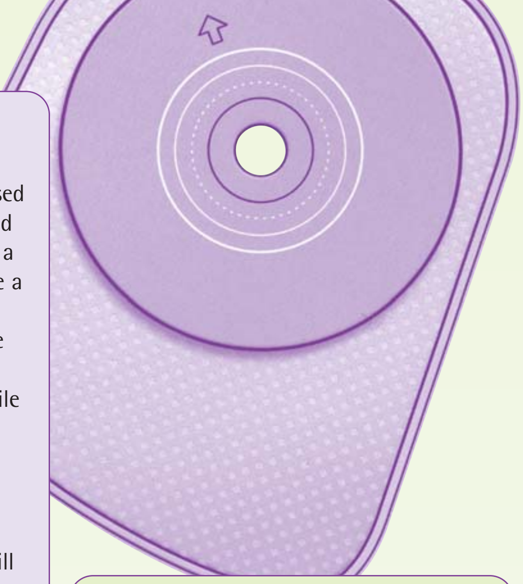
There are those of us who are happy with the pouch we are using and say 'If it's not broke don't fix it'. However, if you are having problems remember there are about a dozen companies manufacturing ostomy appliances and each one has a very wide range of different pouches. There is one out there to suit you.

Mix and Match- Different pouches for different occasions.

The same pouch usually comes in closed and drainable versions and is produced in different sizes. If you normally use a closed pouch it is a good idea to have a few drainables and possibly a smaller size as well. Drainable pouches will be useful if you have a stomach upset which results in loose motions, or while travelling it might be easier to empty rather than change a pouch. And remember to take a small supply on holiday – just in case.

If you use a two-piece system, it is still possible to "ring the changes" – drainable and smaller pouches and stoma caps are all available to fit the same base plate.

A colostomy "plug" is also available. However, it is only produced by one manufacturer and it should not be used without consulting a stoma care nurse to ensure it is suitable for your type of stoma.

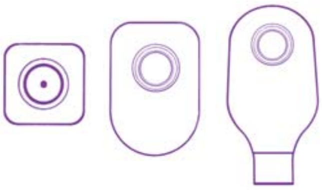


Bag or Pouch

Up until now in Tidings we have used the word bag when referring to a stoma appliance. However, this article uses the word pouch instead.

Is it better to talk of pouches or bags? Let us know what you think.

Types of Pouch/Bag

	Advantages	Disadvantages
Closed pouch 	• More suitable for coping with formed motions. • Replaced with a new pouch one to three times a day. • One manufacturer produces a flushable version, which can be disposed of down the toilet.	• Less suited to managing a more liquid output. • The pouch may need to be changed and disposed of while away from home. • Some people may find it difficult to empty a non-flushable pouch, prior to disposal.
Drainable pouch 	• More suitable for coping with a liquid output • Does not require changing as often as a closed pouch. • Fewer pouches are used. • Easily emptied, prior to disposal.	• May be difficult to empty if the output is of a thicker consistency. • Careful cleaning of the outlet is required. • Clip or fastening can be uncomfortable.
Two-piece system 	• Flange (base-plate) can remain in place for two to four days, which is kinder to the skin. • The "stick on" system may be easier for ostomates with arthritis. • The "clip on" system may be easier for visually-impaired ostomates.	• Some people may find it difficult to keep the flange (base-plate) clean. • Leakage behind the flange may remain undetected and lead to sore skin. • Some systems are fairly rigid and bulky.
One-piece system 	• Less bulky and more flexible. • May adhere more securely to scarred or uneven skin.	• Every time the pouch is changed it has to be accurately positioned around the stoma. • Frequent changing of a closed pouch may lead to sore skin.

Readers' Replies...about Reversal

Andrew Legg

Regular readers may remember in the summer issue of Tidings, Andrew Legg wrote of his experience of diverticular disease and his Hartmann's procedure to form a temporary colostomy. Following our feature on stoma reversal Andrew wrote again to tell us about the keyhole surgery he had to reverse his colostomy and update us on his progress.

When I discovered that a reversal operation would be possible under my employer's BUPA scheme I naturally jumped at the possibility and went to my GP for advice. He referred me back to the surgeon. The consultant outlined all the pitfalls of having the reversal operation and also touched on the benefits. He told me of the risks that could be envisaged and left me very much to make my own decision without influence. He indicated that, if I agreed, he would like to use the laparoscopic (keyhole) technique to carry out the reversal process.

After making a number of enquiries locally, consulting the internet, and, more importantly, discussing it with my family and the stoma nurse team I decided that it was a risk well worth taking. I discovered that my consultant is a leading exponent of laparoscopy and I felt that I would be in very safe hands.

I was booked in for a colonoscopy to check that I had healed well enough and that I was a suitable candidate for the reversal. The results appeared favourable but I was left under no illusions that if, when on the operating table, laparoscopy was not considered appropriate the reversal would be undertaken using conventional surgery.

On May 3rd, just over four months after my Hartmann's Procedure, I had my reversal. Four hours later I was back in my room delighted to learn that the laparoscopic technique had been successful! I had three additional small wounds on my stomach and a very neat "purse" stitching on the site of my stoma.

I was well enough to return home three days later and the district nurse visited me every other day to change my wound dressings. The three small wounds healed quickly and the staples were removed after ten days. I was in almost no pain and was able to be up and about immediately on my return home. I admitted to some tiredness but this was only to be expected. Remember I am now sixty-seven! The stoma wound naturally took much longer to heal as the flesh had to be kept clean and granulate from the inside. The purse stitch was removed after twenty days and I felt fine.

I had only one minor scare after being home a week or so when I had a quite severe bout of diarrhoea and passed quite a lot of blood. Phone calls to my GP and to my consultant reassured me and after a couple of days I was back to normal.

I returned to full-time work four weeks after the operation and I have had no relapses, pain, or problems whatsoever apart from a little tiredness. My bowel function returned to normal very quickly and has been regular ever since. Six months on I feel fine and have just had my final sign-off from the consultant. With, I hope, many years ahead of me I am sure the reversal was the correct step for me.

George wrote to tell us why he decided against a reversal.

I found the articles on reversal in the last issue of Tidings very interesting as I have a colostomy as a result of bowel cancer three years ago. After chemo I made a full recovery and was offered a reversal and even got as far as the pre-op stage - my surgeon was excellent throughout, not pushing me one way or the other.

But at sixty-four years old after years of IBS I feel as well now as I felt in my twenties.

With the help of my wonderful wife I have very little trouble with the bag and am now as regular as clockwork.

The point I am trying to make to anyone contemplating a reversal is that it is a very personal decision and if you have any doubts don't be pressurized into it, don't feel a coward, don't feel guilty and, most importantly, don't feel a failure.

Sue wrote to relate her experiences and also to stand up for those ostomates who have decided not to be reversed.

I was given an end colostomy during emergency surgery in July 2006. I had suffered a perforated bowel due to diverticular disease and an abscess. I had no idea I had diverticulitis but now had a reason for having been controlled by my bowels for years: never being able to leave the house unless I knew journey time and location of toilets along the way and at my destination.

Following the usual highs and lows that come after surgery I soon got used to my new friend and christened him “Bob”. I returned to health and went back to work after two months, not the three months recommended by my surgeon. I started doing yoga again and then began running every morning. I now had to weigh up the pros and cons of having “Bob” taken away from me and be ready with a decision for my surgeon when I returned to see him after six months.

While trying to make up my mind I noticed that my life had taken on a new type of freedom: I could go out any time of the day I wanted, I didn’t have to cut telephone calls short to go to the loo, I was going out all day with friends and family and my fitness level was better than ever, in fact I was living my life!

When I returned to see my surgeon I told him I didn’t think I was ready for a reversal. ‘That’s fine’ was the reply. He felt that since there were no problems with my stoma, no prolapse or a hernia, and I was happy with it he would rather not put me through the trauma of surgery if he didn’t need to. However, the option is always there for me if I can’t cope with “Bob” any longer or I develop a problem.

Now over a year later I cannot imagine being any other way. “Bob” and I are very happy and my bowels no longer control me. My husband says I am far more relaxed than I have ever been and we enjoy a better level of intimacy than we ever did. I often ask my husband if he would prefer me back to normal. His reply is ‘But this is normal isn’t it?’ That for me says it all.

I know keeping your stoma is not for everyone but for some of us it really does give you your life back and with a little patience and full acceptance of your situation you can learn to love your “Bob” too.

Mary, aged seventy-nine, has been through a reversal and would like to share her feelings with readers having to make a decision about it.

Having come through three years of cancer in the late 1980’s with several operations and chemo and radiotherapy, I went into remission during the 90’s. However, it came back in 2000, this time in the rectum where it joins the colon. Part of the colon and the whole of the rectum except for about an inch at the bottom (anus) were removed and I was given an ileostomy. ‘Don’t worry,’ the surgeon said gaily. ‘As soon as the colon has healed, we’ll join you all up again and you’ll be back to normal.’ What a joke!

After the reversal operation, I came round to more pain than I had experienced in any of my former operations, which included two for adhesions and blockages, one kidney removal and a hip replacement. That was a foretaste of the next two years. I had no control whatsoever over my output and had frequent “accidents”. I learnt that this was because the colon produces waste all the time. It is then stored in the rectum to be evacuated once or twice a day – but I had very little rectum left! My anus got so sore, I could hardly bear to wipe it, and it is still sore to this day. So my social life was severely curtailed.

After two years, I was transferred to a bigger hospital and I came under the care of a colorectal specialist. I explained the situation and asked for a colostomy. He said I should have had one in the beginning. So I had the colostomy operation on Christmas Eve 2004. It was a long operation because the whole area was thick with adhesions.

So what I would like to say to readers is, ‘Ask for more information before deciding. If you have had your rectum completely removed for whatever reason, don’t have a reversal operation. If only your colon has been affected, then when healed, it could safely be joined up again and you would have no problems, I suppose.’

Three different opinions. How do you decide?

To help you make the most appropriate “informed” decision for yourself, two stoma nurse specialists produced a simple checklist which we published in the last issue of Tidings.

- Make sure you understand why your stoma was formed in the first place.
- Ask your consultant or nurse specialist to provide you with detailed information regarding the proposed surgery and the realistic outcome you can expect in relation to hospital stay, length of recovery and expected bowel function - both in the short-term and long-term.
- Consider what your quality of life is like with a stoma.
- Consider what your quality of life would be like without a stoma, taking into account all the surgery and treatment that you have had.
- Speak to people who have undergone a similar procedure.
- Ask for a written summary of your consultant’s plan.

In the News...

Colostomy Association Trustees
at the House of Commons

On the 11th December, Sue Hatton, Beryl and Ray Goddard attended a reception at the House of Commons which was hosted by Dr Roger Berry M.P. and Stephen O'Brien, the shadow Minister for Health. This event, sponsored by Coloplast Ltd, provided representatives from patient and nursing groups, with the opportunity to meet M.P.s and explain exactly what the proposed changes in the supply of ostomy appliances and the provision of services would mean to them. Senior staff from Coloplast were also present and they explained how the proposals could result in significant reductions in the range of products that they would be able to offer to their customers.

By the time you read this magazine the latest round of Department of Health consultations will have closed. A response has been formulated on behalf of the Colostomy Association and was despatched to meet the 28th December deadline.

Ray Goddard, Office Manager, Trustee and Treasurer, says...

'On behalf of CA I would like to take this opportunity to thank those who used the draft wordings, from the last issue of Tidings and wrote to their M.P.s. We have been advised of more than fifty M.P.s, who have replied to their constituent's letters and the Minister of State for Health, Dawn Primarolo, is, I am sure, now fully aware of the depth of feeling that these consultations have provoked.

We are now anxiously awaiting the outcome of this round of consultations and as soon as they are published we will provide an update on the News Page of our website www.colostomyassociation.org.uk.

I am sure that this will not be the end of the line for these proposals, but rest assured that, whatever the outcome, we will continue to be actively involved in making sure that colostomates within the U.K. do not suffer a reduction in either the service that they currently receive or the range of appliances available.'

Is Margaret the oldest person with a Colostomy in the UK?

Margaret Sinclair, nee Robinson, celebrated her 100th birthday on 31st December last year.

Born in a cottage in Ramsbeck,on the shores of Ullswater, Margaret loves to share memories of a happy childhood. At fourteen she would cycle from Mossbank near Gretna to work at Carrs biscuit factory in Carlise. At twenty-four Margaret left work to marry Edwin Sinclair and they had one son, James. Now Margaret is a great, great, great grandmother.

She lives at home alone with support from family, "home carers", a regular "Crossroads" visitor and others. Despite being profoundly deaf and partially sighted, Margaret has an excellent sense of humour and often wonders if she is the oldest person in the UK who has a colostomy and laughs about this. Until very recently she proudly and quite meticulously managed all aspects of her stoma care.

Diamond Wedding Anniversary

Lily and John Young, from Stevenage, celebrated their Diamond Wedding Anniversary on 22 November 2007. Lily, aged eighty-one, had major surgery four years ago and now has a colostomy. Two years later a tumour was found on one of her kidneys and she underwent a second round of major surgery.

Lily has recovered well and enjoys life with her family and close circle of friends. Her husband, John, has looked after her well as she has done for him during their many years together. They are "over the moon" to be celebrating sixty years of marriage and spent their special day with their family whilst holidaying in Cornwall. They are looking forward to the arrival of their first great grand-child in January.

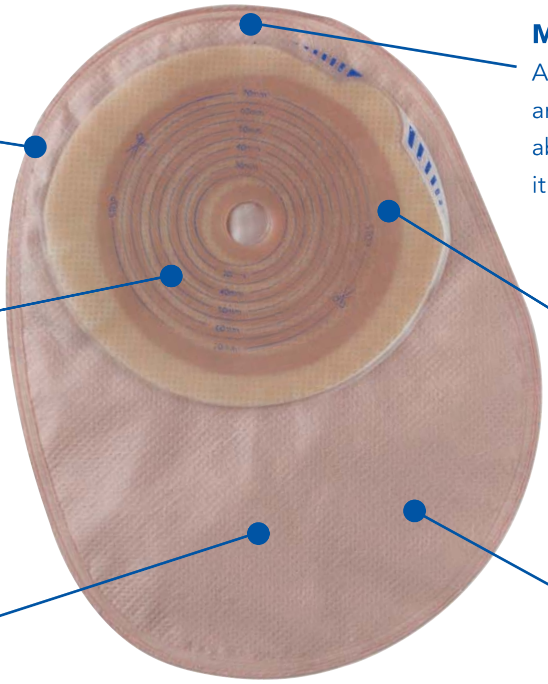
Salma Ahmed wins Award for Achievement through Adversity

The Lord Mayoress of Bradford presents fourteen year old Salma Ahmed with the trophy for winning first place in Manningham's Young People's Award for Achievement through Adversity. You may remember Salma wrote about her experience of Crohn's disease and having a stoma in the summer issue of Tidings.

From Abroad...

Changes in eligibility to the French Health Service

1. Newcomers to France who do not have an E106, or an E121 (as retirees), and are not intending to work in France, will not qualify for admission to the health service, and will have to fund their own medical treatment, either directly or by purchasing full private health insurance.
2. Those who are currently in the health service by virtue of an E106 form will be excluded from the health service when it expires, and will have to fund their own medical treatment, either directly or by purchasing full private health insurance, unless they take up employment in France. A possible concession for those whose health is such that they would be unable to work or to obtain private health insurance remains unconfirmed.
3. Those currently residing in France who do not qualify for an E121 because they are below state retirement age, are not in possession of an E106, are not working, and are in the health service by voluntarily paying personal social security contributions from their private income, will not have the right to remain in the system after a grace period of six months, which will end on the 31st March 2008. If they wish to remain in the health service they will have to take up employment in France, otherwise they will have to fund their own health care.
4. Those over retirement age, and therefore holding an E121, will be unaffected, and will remain in the health service.



Update...

on new stoma care products and services

Four companies contacted us with details of stoma care appliances and services that have been introduced within the last few months:

Opus Healthcare have recently launched DeoGel, a deodorising and lubricating gel. As well as deodorising pouch odour it can also reduce pancaking.

The deodorant is especially formulated to breakdown odours rather than mask them with another scent. The lubricant reduces static and thus the likelihood of the plastic sides of the pouch sticking together.

This product is available on prescription (order code: 2010–200ml bottle). Samples can be requested via www.opus-healthcare.co.uk

Cui International has just launched a new range of fully washable and reusable bed and chair pads that offer high absorbency rates. The proprietary fully breathable 3-layer system ensures complete protection in the event of an accident or leak whilst offering optimum comfort. The pads are especially useful when going away but ideal for every day use as well. For further information and contact details please see main advert on page 26.

OstoMART have introduced a brand new odour neutraliser, cinnamon & sandalwood, to compliment their excellent range of OstoMIST sprays. This fragrance is particularly suitable for anyone looking for an alternative to fruit and flowers. Cinnamon & Sandalwood OstoMIST is available on prescription from your usual supplier in either a 50ml or 100ml ozone friendly pump spray. (order code: CSW1-100ml spray, CSW2-50ml spray).

If you would like to try this new fragrance please call OstoMART on 0800 220 300. They will be pleased to post a sample out to you free of charge.

SecuriCare have informed us about Stoma Care Clinics that have recently been established in the community.

Welwyn Garden City
(No appointment necessary)

Venue: QE II Hospital Clinic
Cansearch
Howlands.
Day: Every Wednesday.
Time: 2 – 4pm.

Venue: Queensway Health Clinic
Hatfield.
Day: First Thursday of the month.
Time: 2 – 3pm.

Venue: Hoddesdon Health Centre
High Street.
Day: Second Thursday of the month.
Time: 2 – 3pm.

Venue: Hertford County Hospital
Clinic C.
Day: Last Thursday of the month.
Time: 1 – 2pm.

Wycombe

Venue: Amersham Health Centre.
Day: Third Tuesday of the month.
Time: 2pm – 3pm.

Venue: Cross Keys Surgery
High Street
Princes Risborough.
Day: First Thursday of the month.
Time: 2pm – 4pm.

Venue: Knaves Beech Clinic
Securicare Medical
Compass House
Knaves Beech Business Centre
Loudwater
High Wycombe.
Day: Every Wednesday.
Time: 1pm – 4pm.

For an appointment at clinics in the Wycombe area
Please telephone 01494 426235.

Information on new products and services received before 22nd February 2008 will be considered for inclusion in the next issue of Tidings.

Ray Goddard
Office Manager,
Treasurer and Trustee

Colostomates' Comments

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, do write and tell us about it.

Tidings
Dedicated to Colostomates and their Carers

A mother's story...

When you fall pregnant, you don't ever expect anything to go wrong. You have a vision of a little baby all smiles and happiness... Well, as we found out, it does not always happen like that.

Our daughter was born nearly ten weeks early; she was born with cloacal malformations. This was our introduction to the world of stomas. Hannah had her colostomy formed the day after she was born, and then at eight months old she had major reconstructive surgery. Her colostomy was reversed just before her first birthday. However, after years of constant soiling, in October last year she had the Malone ACE or MACE operation. This allows daily enemas, or washouts, to be administered directly into the bowel, rather than through the back passage.

Life with Hannah and her colostomy was daunting at first. When I signed the consent forms I didn't even know what a stoma was. I just knew she needed it to survive. The constant hospital visits and trips to theatre for one thing or another do become part of life after a while. The enemas, the "bowel management " was an experience I never wish to repeat but now we have the ACE, and everything is working great.

Hannah is now six years old. The one thing we as a family have felt, through our journey so far, is lonely and isolated. Questions like 'She's got what?' and comments like 'Oh I'm so sorry' are not what you need to hear, and give you that feeling in the pit of your stomach that only another parent can understand.

Hannah, now six years old

I searched online one night, researching stomas and such like and I came across an online support community called Ostomyland. Here I met Rachel and we became close friends in real life. I moaned and vented my feelings to her one night just after Christmas last year, and from there came the idea for "Breakaway". The idea was to get the children and the families together, share experiences and have fun!

It was a lot of hard work, sleepless nights and tears. NO ONE could have expected "Breakaway" to be the huge success that it was: children from such diverse backgrounds, with different medical histories, socialising, playing together, creating life-long friendships.

Breakaway was exactly what we had been looking for as a family. We now have no need to feel alone and neither does anybody who was there. I am really proud of what Rachel and I have achieved.

Breakaway 2008 is now in the process of being organised and bookings are being taken. Most of the families from 2007 are coming along again, but we would love to see more new families this year.

Julie Bastin

BREAKAWAY
success...

In August 2007 I spent a weekend away with a group of thirty people: Mums, Dads and children, aged from five to twenty, and I returned feeling most humble! Going away with children suffering with bowel and bladder dysfunction might seem not the most dynamic thing to do...but, my, oh my, you would be very wrong!

These are children with a variety of bowel and bladder problems such as Crohn's disease, ulcerative colitis, congenital malformations or intractable constipation. This meant that they had one or two of the following surgical formations: colostomy, ileostomy, ileo-anal pouch, urostomy, Mitrofanoff, neo-bladder or an ACE - not that anyone would have had any hint of their medical histories.

I had the most amazing time with this group in a very wet and windy Wales. We walked in the rain, we canoed in the rain...in fact everything we did was in the rain. Did it dampen the children's enthusiasm? Not a bit of it, and that being the case it was infectious, we all just got wetter and wetter but enjoyed every minute of the weekend.

It started with us all meeting in the lounge of the Youth Hostel in Bryn Gwynant, all very subdued and sitting in little groups. After supper we began group activities led by pro-active instructors...in the rain! From that time forth we were all friends; talking about medical problems was not difficult. Listening to the children asking what they "had" and what was its name was brilliant and so normal! That horrid word "normal" just didn't have a place; we were all just fine with whatever we had or didn't have. In fact I felt the "abnormal" one by not having had any surgery - not that I was made to feel different.

The next two days were filled with walking, gorge walking, which had to be curtailed due to the fast running river, as was the climbing due to the rain, and, my favourite, canoeing. Oh what fun you can have when soaked to the skin, wearing buoyancy vests and helmets, canoeing across the lake to jump off a rock into ice cold water. Well some of the children jumped in, so there was no option, but for a mad fifty-seven year old stoma care nurse to jump in too! It was almost expected...and what fun!

The finale came with a disco evening. Children, who would not talk at the beginning of the weekend, now singing and dancing together was a sight to behold. As they sang "We are the Champions" at the top of their voices Rachel and Julie, the Breakaway organizers, were reduced to tears...wonderful!

Exchanges of emails and addresses preceded tearful goodbyes, but I'm sure the contacts made will be longstanding.

I hope that Breakaway will go from strength to strength; I'm not sure that Rachel and Julie really know what they have let themselves in for. I am delighted I was able to attend this inaugural weekend and hope to be there in 2008.

Lesley Nickell
CNS Stoma Care
ConvaTec Ltd

Breakaway again...Adventure weekend specifically for kids with stomas and their families...

Break Away 2nd-5th May 2008 YHA National Forest

- Three nights full board accommodation and activities only £150 per person
- Bringing together young people living with bowel/bladder diversions and their families
- Qualified and experienced instructors
- Supported by the Colostomy, Urostomy Asscociations and the UK's stoma care companies
- Funding Available
- Stoma care nurses and camp counsellors on site throughout

email break.away@tiscali.co.uk

www.breakaway-visit.co.uk

BREAKAWAY

2008

colostomy association

hints and tips...for new ostomates

When changing your colostomy bag

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

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

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

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

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

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

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

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

Gentlemen who have a problem with being hairy around the abdomen could try using a “Ladyshave”. It gives a really smooth shave, is much safer than an ordinary razor and less clumsy than an electric shaver.

To protect the stoma while shaving cover it with the lid of an aerosol can.

A water-soluble antiseptic can be used after shaving to prevent a rash or skin irritation.

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

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

Changing your bag away from home

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

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

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

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

Clothing

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

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

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

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

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

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

Patterned swimwear will camouflage any bulges.

Stoma bag covers, which will help to prevent your bag sticking to your skin in the heat, are available from some manufacturers.

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

Dealing with:

Odour

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

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

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

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

Wind

Drinking peppermint tea or peppermint oil in hot water can help to reduce wind.
Eating fennel or drinking fennel tea is another remedy.

Pancaking

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

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

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

Leakage

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

Remember:

- Some medications may change the colour and/or odour of your output.
- Antibiotics may cause diarrhoea.
- Painkillers may cause constipation.
- Enteric coated or modified release tablets are designed not to dissolve until they have reached the latter part of the intestine, so they may appear unaltered in the stoma bag without having any therapeutic effect.

Your doctor or pharmacist will be able to advise you if alternative medication without these side effects is available.

Travel and Holidays

Pack twice as many appliances as you would normally use.

Always take the details of your stoma products and contact numbers for your supplier, in case you need to obtain further supplies.

When flying, take your supplies in carry-on luggage. If this is not possible spread them across several suitcases in case of loss.

On aeroplanes, scissors are not allowed in hand luggage, so prepare any bags you may need during the flight before you leave.

Drainable bags are more convenient when travelling, and essential if you might get struck down with "Pharoah's Revenge". To make them easier to empty introduce a few drops of gel or baby oil before fitting.

Do not leave your supplies in the car in hot weather as the adhesive may melt.

Only drink bottled water when visiting countries where the water supply is suspect.

In hot and humid weather you may find that perspiration causes the flange to lose its adhesion. Check regularly throughout the day and change your bag if there is a problem.

When swimming remember to put the small adhesive patch, supplied with your bags, over the vent-hole otherwise the filter will become damp and stop working.

Macmillan Cancer Support...

Today there are three times more people living with cancer than there were thirty years ago.

One in three people will be diagnosed with cancer at some time in their lives.

At the CA National Meeting Mark Wood, Development Manager, gave a very interesting talk about Macmillan Cancer Support.

He began with a short film showing some of the individuals involved with the charity including cancer patients, nurses and fundraisers.

At the end they all raised their hands in salute and said the words 'I am Macmillan'.

**WE ARE
MACMILLAN.
CANCER SUPPORT**

The presentation continued with an outline of the history of the charity. It began in 1911 and in 1924 became known as The National Society for Cancer Relief, the aim being to provide practical help to anyone diagnosed with this condition. Last year the name was changed to Macmillan Cancer Support, because it was felt that this better reflects the aims of providing practical, medical, emotional and financial support throughout the cancer journey; the word relief implied the control of pain for those whose prognosis was poor.

Another misconception is that Macmillan is only involved with funding specialist nurses. Yes, the charity does do this: the first Macmillan nurse was funded in 1975. By the year 2,000 there were 2,000 nurses; today there are 3,000 as well as other health professionals i.e. occupational therapists, physiotherapists, radiographers all funded by Macmillan. It is usual to fund the post for three years then the NHS will take over, but the Macmillan name remains.

Source of Support

Funding nurses is only one of the many ways Macmillan provides a source of support for those with cancer.

Macmillan's national CancerLine takes 35,000 calls every year.

Macmillan has a directory of 750 self help and support groups all over the country and provides grants of between £500 and £1,000 to help set up such groups. The charity also helps to run "Living with Cancer" courses.

Macmillan provides grants to people affected by cancer: ranging from grants for equipment in the home to clothing grants for people who have suffered severe weight loss.

Other projects include:

A benefit helpline and local benefits advisors who have taken on a total of 7,000 cases and have helped people to claim £11½ million in welfare benefits to which the claimants were entitled.

"Bridges", a scheme based in Birmingham, in which volunteers help in a variety of ways, for example providing a lift to outpatients for treatment, or feeding the dog when people need to stay in hospital.

"Cancer environments" which aim to improve the surroundings in which cancer patients are cared for and treated.

Force for change

Macmillan campaigns on behalf of cancer patients on a variety of issues including:

Establishing standards of care.

Exemption from hospital car parking charges for cancer patients undergoing treatment.

Making it easier for people affected by cancer to get travel insurance.

All this costs £100 million a year, 90% of which is raised by fundraising: collections, marathons and other events.

Macmillan's ambition is to reach everyone affected by cancer by the year 2010.

How to apply for a grant from Macmillan

Having cancer can be expensive in many ways e.g. prescriptions, a special diet, child care or travel to hospital. Macmillan provides a guide called "Help with the Cost of Cancer" which explains what financial benefits are available and shows how to get that help. The guide and further information can be obtained from health centres, libraries, information centres etc., Macmillan website www.macmillan.org.uk or by phoning 0800 500 800

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Please tick to select your preferred film colour:
☐ Clear ☐ Opaque
Stoma Size: .... mm

BCA01/08

Ode to the Stoma Nurse

In the bowels of the NGH (Level one on Huntsman 'B')
Lurk several stoma nurses who tend the likes of me.
These peristomal people, armed with powder, tape and wipes
Know what to do to comfort you, should you contract the gripes.
They cart around more bags and pipes than any Scottish clan
A "washout's" no abandoned game, but a quick flash in the pan.
Adept with gloves and kidney bowls, curved scissors and a measure,
They size you up, there's no escape, to them, it is pure pleasure.
The pat they give your tailored pouch says "Didn't I do well?"
But when it comes to DIY and you cut the hole – "Oh, hell!"
Without these kindly nurses who have a real "bum deal"
We'd never know the meaning of designer bag appeal.
Mini, midi, two-part, velcro'ed, one-piece, take your pick
It's not long till you know the ropes, & changing them is slick.

So thanks to all you ladies for your tender, loving care ~
You made my darned colostomy easier to bear!

A grateful patient
The Northern General Hospital

Parastomal Hernias

A hernia is a weakness in the abdominal wall that allows the contents to bulge out. When associated with a stoma it is called a parastomal hernia.

At the Colostomy Association National Meeting last September there was considerable interest in the two presentations on this topic.

Chris Harmston a Specialist Registrar at the South Warwickshire Hospital spoke about parastomal hernias from the surgeon's point of view.

Mary Jo Thompson, a Nurse Specialist, described a hernia prevention programme for ostomates at the Southern Trust, Northern Ireland.

In the following pages we provide summaries of both these presentations.

Also:

Two colostomates write about their experiences of coping with a hernia.

Adrian March, a CA trustee, who has been an Amateur Swimming Association and National Coaching Foundation tutor for many years, answers an ostomate's question about swimming. Adrian also suggests how new ostomates might reduce their chance of developing a hernia.

- Have you had a parastomal hernia repair?
- Was it successful?
- Has the hernia returned?

Please write and let us know about your experience.

What you need to know about Parastomal Hernias

At the CA National Meeting in September 2007 Chris Harmston MBChB, MRCS, Specialist Registrar at the Warwickshire GI Unit of The South Warwickshire Hospital, gave a very clear explanation of what a parastomal hernia is and why they occur. He went on to discuss how they can be prevented and what can be done once they have developed.

Most people have heard of hernias – Gazza had one! A hernia is a weakness in the abdominal wall that allows the contents to bulge out, forming a lump or swelling. They are a common problem and form around 10% of the general surgical workload.

A parastomal hernia is a hernia related to an abdominal wall stoma. It is difficult to say how common these are because different studies have come up with a wide range of figures. This is because patients have been asked different questions or been followed up for different lengths of time. However, it is clear that the incidence varies with the type of stoma. Studies have shown that between 4% and 48% of patients with an end colostomy have a hernia, for a loop colostomy results vary from 0% to 30.8%, for an end ileostomy 1% to 28% and a loop ileostomy 0.6% to 2%. So it seems that colostomates are more likely to have a hernia than ileostomates and that they are more likely to occur with an end rather than a loop stoma (although this is to be expected as temporary stomas are only in place for a short time). Most parastomal hernias occur in the first two years, although it has been known for them to develop after more than twenty years.

Although most hernias do not give rise to symptoms, ostomates who have them often notice a swelling at the stoma site or experience mild discomfort or a dragging sensation. If a section of bowel becomes trapped within the hernia this can cause an obstruction and the stoma may stop working. A hernia around the stoma may also lead to problems in fitting an appliance.

To confirm the presence of a stoma a doctor will take a history (ask questions) and then examine you. The doctor may ask you to remove the pouch so that he can observe the area around the stoma while you are standing up and lying down. He will ask you to cough or raise the upper part of your body off the examining couch, both of which increase the pressure within the abdomen making a hernia more apparent. A doctor will also use a finger to examine the inside of the stoma.

If further tests are required then an ultrasound scan may be arranged. A CT scan may occasionally be requested if it is suspected that a loop of bowel may be trapped by the hernia. It is possible that in the future MRI scans may be used.

What causes a hernia?

Like other hernias there are general factors which make the chances of developing a parastomal hernia more likely. These include being overweight or, on the other hand, malnourished. An increase in pressure within the abdomen or cancer can also contribute. Steroid drugs can make abdominal muscles weaker and as we get older muscle tone diminishes, both of which increase the risk of a hernia.

To minimize the chance of a parastomal hernia developing, surgeons aim for the smallest size of hole that allows for the passage of the bowel without it being so tight that it affects the blood supply to the stoma. A CT study has shown that an opening of more than 3cm increases the chance of a hernia occurring. Bringing the bowel out through the rectus abdominis (“six-pack”) muscle is generally considered to reduce the chance of a hernia although there is no convincing evidence that this is necessarily the case.

Prevention

Some surgeons use a synthetic mesh as a supportive structure around the stoma when it is formed to prevent a hernia developing in the future. The results of studies to evaluate the effectiveness of this technique are encouraging. However, they have only involved a small number of ostomates who have been followed up for a short time, so much larger studies are needed before there is sufficient evidence of success to make this a routine procedure. Also the inserted mesh has a theoretical risk of infection as it is a foreign material, but the studies have not confirmed this risk.

Managing a hernia

Most hernias can be managed conservatively i.e. without resorting to surgery. An operation is considered in emergency situations i.e. strangulation or obstruction, or if there is difficulty in maintaining a seal between the skin and an appliance, leading to frequent leakage. A hernia repair may also be undertaken during surgery for another complication or if the hernia is a source of pain. Where the hernia is causing embarrassment, because it is apparent even when fully clothed, a surgeon may be willing to operate, provided the patient is aware of the risks.

Surgical repair

There are different methods of repairing a hernia; some will be carried out through an incision in the abdomen (open surgery) others can be done laparoscopically (by keyhole surgery). A local tissue repair i.e. making the hole smaller, is a relatively simple procedure, but there is a 50% to 100% chance of the hernia recurring. Relocation i.e. moving the stoma to another site, is a bigger operation involving a larger incision but the chance of the hernia recurring is lower at 30%. A mesh repair was first described in 1977. Today for this type of operation the recurrence rate is only 8%; problems with infection are infrequent and rarely does the mesh have to be removed. This has become the "gold standard" repair.

Chris Harmiston concluded his very interesting and informative presentation by pointing out that parastomal hernias are common and usually do not cause a big problem. However, he reassured us that, where appropriate, they can usually be effectively treated. Also at the time stomas are formed surgeons can take steps to prevent hernias occurring in the future, and it is hoped that this will become a routine procedure.

Coping with a Parastomal Hernia

Two colostomates share their experiences

Paul Foulger

In November 2000 I was diagnosed with squamous cell cancer, a form of skin cancer attached to tissue in the pelvic area. At the time I was told that the tumour was too large to operate on. I would need chemotherapy followed by radiotherapy to reduce its size. It was here that my cancer journey began for a second time. I had been unfortunate enough to have Hodgkin's disease when I was in my early twenties and it was thought that the two might, in some way, be related. The next six months or so were quite traumatic. Then in May 2001 I had surgery. I was warned that I might have two stomas, but in the end I finished up with a non-reversible colostomy following a perineal resection.

Following the operation everything seemed fine and after a couple of months I was able to start irrigation as a regular routine. I now have full control over normal bodily functions most of the time.

Within about six months of surgery I started to develop a parastomal hernia. At first it was about the size of a tennis ball, but gradually it increased until at times it is more like half a melon. The hernia itself has not been too much of a problem. However, it is very important to take care of it. Initially I was prescribed a specially made, corset-like belt. The aim is to keep the hernia under control and a good belt is really the correct answer. The difficulty has been to find a belt or appliance that is comfortable enough to wear all day long.

I have had a number of discussions with my surgeon regarding the hernia. His response has been that he can do something with it, but it would mean another major operation and there is no guarantee of 100% success. The real answer is that, as long as I can put up with the inconvenience, it is better to leave well alone. There are lots of things that can be done today: for example placing some mesh where the stoma is made initially. However, whilst this may help in the early days, there is no long term guarantee.

Living with the hernia has not been so bad provided I take care to wear a suitable support during the day, particularly if I am going to do anything strenuous. I have tried a number of belts and appliances: the most successful have been a Sash belt and an Eakin support belt, I use the Sash belt if I am doing anything strenuous or if I have not worn a belt for a couple of days, and the Eakin belt most of the time.

A word of warning though: do not ignore your parastomal hernia otherwise you could be in trouble. About three years ago I had not worn my belt for two to three days and I had irrigated as normal but without much success. Later that night (Saturday) I began to get a lot of discomfort, and in fact the pain became almost unbearable so I rang the emergency doctor at about 2.00 am. His advice was to ring for an ambulance and get into hospital which I did. After some morphine to kill the pain I began to relax, although the pain was still there. I had developed a strangulated hernia: believe you me it is not pleasant and extremely painful. Once on the ward I was able to lie down and gradually the pain dissipated. On the Monday morning my surgeon happened to be doing his round on the ward. He examined me and showed me how to manipulate the bowel back through the hernia. Since that time I have treated my parastomal hernia with a lot more respect.

At times I feel it is a nuisance, but at least I have got through the cancer journey and survived and am enjoying life to the full, so the respect for my hernia is really worth while. Living with a parastomal hernia isn't so bad as long as you remember to be sensible and wear the correct support.

Gloria Hadfield

'Yes, you have a hernia!' I was told cheerfully by a Stoma Care Nurse at an information meeting.

I wasn't cheerful at the news. I was horrified, even though I had suspected it already.
It was a few years since I'd had my colostomy and it had always bulged a bit but the bulge was getting bigger and the hernia diagnosis left me thinking it was soon going to be enormous.

The surgeon I consulted reassured me that of course it doesn't happen that way but that the hernia would most likely grow gradually more pronounced. I am certain, though, that it would be bigger than it is if I had not started wearing a support.
First of all I bought a 'girdle' from a lady's underwear department and, being handy with scissors and a sewing machine, fashioned a hole in it to pull my stoma bag through. This was OK but a blessed nuisance every time I answered a call of nature, especially if the bag were not empty.
Then I was fitted at the hospital with a "corset", complete with hole again. I wore it all the way home in the car – about 30 minutes – but couldn't cope any longer than that. The corset was tight – too tight – but the hole they had made was too big so not a great deal of use.

The pressure needs to be immediately around the stoma, where the problem is. A problem I had until then was that anything tight over the stoma meant that when it got active I ended up in a mess because my bag got forced off. It was always like that.
One New Year's Eve, all dressed up in high heels and skirt for a change, I had to go and change in the middle of a celebration dinner when "that smell" drifted up from my lap. That was when I remembered why I hadn't worn tights in a while! So then I found the SASH belt. This was such a relief. Made to fit the bags I wore, it worked where needed and held my bulge in quite well.
This was the point at which I should have gone back to my exercise classes. When I was diagnosed with rectal cancer in 1996 I was fitter than ever in my life and enjoyed aerobics classes and step aerobics especially. After surgery I started swimming a soon as I could and got myself back to real fitness. Then the hernia. In my panic I gave up exercising 'for a while' until I felt I had my situation under control again. But, getting older, I never seem able to regain the stamina I once had and that is something I really regret. These days I have to be content with walking.

So I wore the SASH every day for some time. Then, when I wanted to look my best for a wedding in the family I asked my Stoma Care Nurse if I could learn to irrigate.
My surgeon agreed, she taught me how and I am still successfully irrigating.
This means that I can wear control pants (or tights!) between irrigations because my stoma doesn't work then. They hold in my bulge and, I believe, stop my hernia from getting worse.

I really would not like to be without support, especially when out walking but even indoors or just round and about. A stumble, a missed step, and I can feel my hernia give a bit more.

My surgeon said that he would repair it if I wanted him to, but warned that anything other than a complete re-siting of the stoma would not be recommended. This would probably involve a few hours of surgery because it is extremely likely that there are adhesions from the original operation to hinder progress. As my GP says, you don't volunteer for such extensive surgery when it isn't vital.

I felt at first quite aggrieved that no-one told me I ought to wear a support, especially whilst exercising. There's no proof that was what caused my hernia but I can't help feeling that it might have helped if I had worn a belt from the start. That wasn't the advice given ten years ago, but I understand that there is now evidence to suggest that stoma patients who wear a support of some kind are far less likely to develop a hernia.
As it is my hernia is unsightly when I am not dressed and uncomfortable if I don't wear a support. But I go on irrigating, pulling in my bulge with my firm 'Shapewear' from a high street store and hoping that I can continue this way for a long time to come. I know I may need surgery one day but hope to put it off as long as possible.

Do you have a parastomal hernia so close to your stoma that support garments currently available are ineffective?
It may be possible to provide a solution. If you would be interested in pursuing this please e-mail adrian.march@orange.fr

Hernia Prevention

Mary Jo Thompson, Stoma/Coloproctology Nurse Specialist, also gave a presentation on hernias at the CA National Meeting. She described a prevention programme that she developed, together with her colleague, Bernie Trainor, at the Southern Trust, Northern Ireland.

The aim was to provide new ostomates with information and advice about how they could reduce their chance of developing a parastomal hernia. The effectiveness of the programme was evaluated by comparing the percentage of new ostomates who developed a hernia before the programme began with the percentage who developed a hernia after the programme was introduced.

Prevention Programme

On discharge, patients were advised to avoid all heavy lifting (defined as a full kettle or heavy shopping) for three months following surgery.

Three months after their stoma operation:
1. Patients were advised of the potential risks of the development of a parastomal hernia.
2. Abdominal exercises were taught and demonstrated and patients were advised to undertake these exercises daily until one year after their surgery.
3. Patients were measured and support belts or girdles were ordered. They were instructed and encouraged to wear these whilst lifting or undertaking heavy work.

Patients were monitored for one year after their operation at regular intervals (three months, six months and one year) and the above advice was reinforced at each clinic appointment.

In the year before the programme was introduced (August 2001 – July 2002) 28% of ostomates developed a hernia within a year of having a stoma.
When the programme was introduced, during the first year (August 2002 – July 2003) the percentage of new ostomates developing a hernia fell to 14% (a statistically significant reduction).
During the second year (August 2003 – July 2004) the percentage was 17% but on further examination, after compliance to the programme was examined, this dropped to 10%.

These findings support the need for patients to develop and maintain strong abdominal muscles to help prevent the development of a parastomal hernia and they recommend doing this by exercise, avoiding heavy lifting in the first three months and thereafter supporting their abdomen whilst heavy lifting.

A full account of this study has been published in Gastrointestinal Nursing see:
Thompson MJ, Trainor B (2005) Incidence of parastomal hernia before and after a prevention programme. Vol 3 No 2: 23-27
Thompson MJ, Trainor B (2007) Prevention of parastomal hernia: a comparison of results 3 years on. Vol 5 No 3: 22-28

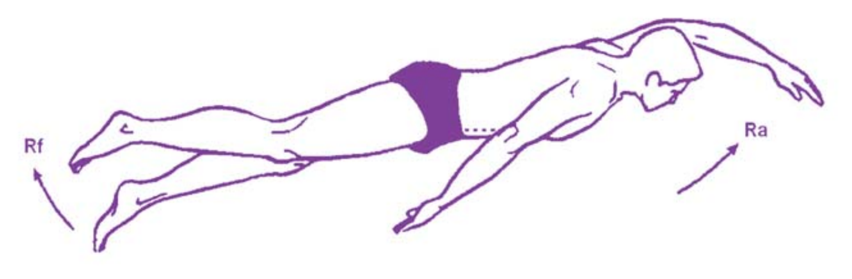
Mary Jo Thompson
RGN, BSc, PGDip, MSc, ENB216

Swimming after Stoma Surgery

An ostomate at the National Meeting asked the question: Which swimming stroke is least likely to contribute to the development of a hernia? It was answered by Adrian March, a CA trustee, who has been an Amateur Swimming Association and National Coaching Foundation tutor for many years. Adrian suggested that breast stoke could impose undue stresses on the rectus abdominis muscle and therefore crawl might be better, with his preference being for back crawl. Adrian was concerned that his reply was inevitably over-simplified, and has written a fact-sheet on this topic of which an abridged version appears below.

How Swimming Affects the Body

To understand what is happening to the body when swimming, it is necessary to consider the forces which the water exerts on the body. In the diagram of a front crawl swimmer we see the arms push down and back, so the resistance of the water gives rise to a reaction on the arms forwards and upwards (Ra). In the same way the legs are alternately pushing down, so that there is an upward reaction (Rf). These two reactions, Ra and Rf, would have the effect of folding the body upwards like a penknife, with a hinge at about waist level.This can only be prevented from happening by tension in the rectus abdominis, represented by the dotted line in the illustration.



Some Basic Anatomy

Almost everyone will have seen either a skeleton or a picture of one, and will be aware that the major motor muscles of the arms are attached to the upper part of the torso, and those of the legs are attached to the pelvis. The only skeletal connection between the two is the spine of which the lower part is, or should be, fairly flexible. When we stand up, we are prevented from collapsing in a heap by the postural muscles in the vicinity of the waistline: the muscles of the lower back, the obliques at the sides, and the rectus abdominis at the front. The rectus abdominis, popularly known as the "abs", runs from the lower part of the rib cage to the pelvis and excessive stresses on this muscle can, in some cases, lead to a hernia.

Front Crawl

It is not generally appreciated that a front crawl swimmer in competition is pushing the rectus abdominis to its limit. Accordingly, the initial advice on front crawl to a former competitive swimmer would be "Swim at warm-down intensity", to a recreational swimmer "Take it gently", and to both, the universal recommendation "Stop if it hurts".

Breast Stroke

For breast stroke, initial advice must be "Take it gently". Many recreational swimmers tend to draw the knees up under the body, with the result that the water is hitting two large vertical obstacles, and generating substantial drag forces. These forces can be minimised by aiming to lift the feet up towards the buttocks, rather than by bringing the knees under the body. Try also to keep the legs, with the exception of the feet, within the width of the body. It would probably be useful for a swimmer who is doubtful of his or her breast stroke action to request some advice from an instructor at the local pool.

Back Crawl

Back crawl has to be the initial recommendation for swimmers after abdominal surgery, because the reaction forces are resisted by the muscles of the lower back. The only caution, which applies to all swimmers, is to be careful how you stand up. The usual technique of vigorously taking up a tucked postion, in order to enable the body to be rotated more easily from the horizontal to the vertical position, is best avoided, and the advice should be "Stand up slowly".

Butterfly

The basic advice for any colostomate after surgery who wishes to swim butterfly is "Don't". It wouldn't be too much of an exaggeration to say that this stroke is swum with the rectus abdominis, and it can't be done gently.

Other Water Exercise Activities

Apart from swimming strokes, enthusiasts will probably be interested in starts and turns. The fundamental principle must be to consider what use you are making of the rectus abdominis. Starts should be no problem, because the action is invariably one of straightening out, but every turn involves a tucked position, which has to be taken up briskly to enable a good leg drive off the wall to be obtained. Anything more than a gentle turn should wait until you are quite confident about your rehabilitation.

Exercise in water can be excellent, but if you are looking for a class, not all aqua aerobics teachers are equal. The Aquafit Teacher certificate has to be regarded as the top qualification for water exercise. Explain your circumstances to the teacher, who should be able to advise you on any exercises you should omit, or take gently.

Adrian March MA. PhD.

Swimming enthusiasts who would like more detail can obtain a copy of the complete technical note,"Swimming after Stoma Surgery", which includes advice about diving, by e-mailing adrian.march@orange.fr or contacting CA head office.
"Scuba with a Stoma" is also available on request.

Take Care!

Ten suggestions to reduce your chance of developing a hernia. They have been written with new ostomates in mind, but even those who have had a stoma for some time might find a few of them useful.

1 **DO** remember that your protection from a hernia depends mainly on the integrity of your principal abdominal muscle, the rectus abdominis (popularly known as the "abs"), which runs down your front from the lower part of the rib cage to the pelvis.

2 **DO** ask your surgeon whether there is any medical or surgical reason why you should not exercise to strengthen your rectus abdominis. If you are given the all-clear, undertake a proper exercise programme. Even if you were quite fit before surgery, work through the easier exercises first, and always "Stop if it hurts!" Gentle smooth progressive stretching will do you no harm, but don't bounce into a stretch; this is known as ballistic stretching, and should be avoided.

3 **DO** wear a support when undertaking heavy work if you have been advised to do so.

4 **DO** keep your body weight under control: being overweight is an invitation to a hernia. Work out your Body Mass Index (BMI), which equals (Weight in Kg) divided by (Height in metres)^2. If your BMI is over 25, take steps to reduce it.

5 **DO** beware of any activity which causes you to hold your breath. This increases the pressure in the abdomen and therefore places increased demands on the abdominal muscles. If it makes you grunt, then it's causing an increased abdominal pressure, and indicates that caution is advisable. So if in doubt, apply "The Grunt Rule!"

6 **DO** be careful about lifting: consider whether what you are proposing to lift is reasonable, and think about the best way to lift it. Keep the weight as close to the body as possible, at all times, and make sure that you can keep your balance.

7 **DO** think carefully about moving furniture. If you can slide it, preferably with your knee, that's fine, but think twice before you bend over and heave it. If you have a problem reaching the top cupboards in the kitchen, invest in a KickStep, which you can push around with your foot, and step up on to it comfortably.

8 **DON'T** kneel for too long when weeding the garden - try to keep moving. If you find it difficult to stand up from a kneeling position, consider using a kneeler, with support bars which you can hold to push yourself up.

9 If your favourite exercise is running, **DO** make sure that you run on a good surface. The consequences of a stumble, on a bad surface, could be serious.

10 If you enjoy riding, gentle hacking or basic dressage should pose no problems, but leave jumping until you can be more confident about your abdominal muscles. **DO** think carefully about how you will mount the horse - better to use a milk crate, or even two, to start with.

Adrian March MA. PhD.

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.

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The road to recovery...

So where do I start "My Operation" story? I think it is in 1995 when I had cancer of the cervix (extending into my womb) diagnosed. The treatment recommended was to have five weeks of radiotherapy, followed by a direct application of radioactive material to the site, technically known as Gamma med. An operation to remove my womb would complete the process.

So a relatively intelligent person having had one brush with the dreaded cancer would not ignore symptoms that should have rung some alarm bells, would they? Oh, yes, they did: the massive weight loss, Loperamide for three months to treat a dodgy stomach, and an inability to sit for more than an hour driving a car without rushing to the nearest toilet. Well I had recently divorced, changed my job and was trying to rebuild my social life. I hadn't got time to be ill had I? WRONG...

A tentative embarrassing conversation with my local GP led to an appointment for a check up with the surgeon who had diagnosed my original complaint. He tried not to be too negative, but gave me the news that I again had cancer. I had no illusions about the gravity of the situation. I had two options. Firstly, I could have an urgent operation to remove the tumour which was almost completely blocking my bowel, so that it was in danger of bursting. Following this, I would be referred to oncology and pain management teams who would ensure that I would be helped in every way to have a dignified death. Secondly, there was a very slim chance, in fact 5%, of surviving an operation which would be performed a few weeks after the first operation. This was called a Total Pelvic Exenteration which would remove my bladder, my bowel and a lot more besides.

So no choice there then. My only stipulation was that I had every possible test available to ensure that the cancer had not spread outside the areas already discussed, as I was not going to waste enormous amounts of time and money if it had already spread further. An MRI scan, CT scan, blood tests and other tests, long since forgotten, were followed by a further appointment where I was given the good news that the team had discussed the case and were willing to take me on. The recommendation and the reality was that I should have the emergency operation without any delay, followed by a nice sunny holiday (which was an idyllic week in Eilat) and then, when all the members of the operating team could be co-ordinated, the operation would go ahead.

Telling the children has to be one of the hardest things I have had to do. I called the three of them with respective wives and girlfriends to a joint family meeting. For once in my life I could not waffle on, nor could I tell them anything but the whole truth. To this day I don't understand how we all maintained stiff upper lips, but we did. The bare facts and the decision reached were discussed matter-of-factly over a cup of tea. Each of us reacted with rage, the disbelief and the tears that inevitably must follow, in private and in our separate ways.

And so it came to pass that on a chilly day in February 2002 I was admitted to hospital to await my exenteration on February 13th (Oh dear). However, there was one emergency too many and my operation was delayed by one day: and so I have more than one reason to buy myself flowers on Valentine's Day.

My abiding memory of the pre-op preparation was being told that I was to have an epidural. In my innocence I stated that I would really rather not be awake during the operation, to be told laughingly that this was going to be in addition to the normal anaesthetic. I am afraid I'm not sure how long the operation took. I only know there were three surgeons involved and I woke up in ICU hours later. Shortly after I regained consciousness the Macmillan nurse assigned to me came in with the good news that the team had managed to remove all the tumour with a good clean margin and all involved were happy with the outcome so far. I was now the proud owner of a Urostomy and an Ileostomy. With the help of a small amount of morphine I drifted through the next few weeks, gradually learning how to change the bags and finally put on some weight until I was able to cope totally drug free.

The next big step was convalescence. I would stay with a friend down in Kent and gradually get back to normal. Having settled in I expected to regain my strength but to my surprise I became increasingly tired: sleeping in until mid-day, but still feeling exhausted. The crunch came in the middle of one night when I had what I thought was a haemorrhage. An ambulance was called and I was taken to hospital. I underwent many more tests and it was found that instead of healing internally, as had been hoped, I had an ostrich egg sized cavity which had filled with fluid and I had developed septicaemia, I was anaemic and suffering from a B12 deficiency. I was moved into isolation and put on a strong antibiotic regime, given a transfusion and injected with B12. Visitors had to wear masks and be extra careful with hand washing on entering and leaving the room.

The next couple of months passed in a haze. The B12 deficiency and the amount of trauma I experienced in a relatively short time left me with a short term memory loss, which persists to this day. Friends and relatives have told me that on asking me at tea-time what pudding I had eaten at lunchtime, I would always say cherry pie and custard (must be my favourite). I cope now by having a large diary near the phone, so that when friends call I can write in planned outings or meetings straight away.

I finally got back home in December 2002 and started the business of getting better in earnest. I don't know where the past five years have gone because they seem to have flown by. In 2003 I got a very old dog from a rescue centre; he gave me a reason to get up in the morning and go for gradually longer walks. Later that year I started driving again and gained a bit of independence. I started computer lessons and passed an IT exam. Finally in 2005 I went back to work and I enjoy earning some money, the good company, and chatting to customers about their DIY projects. I have recently been on some interesting holidays to Dubai and China, as well as trips to some of the historic and scenic parts of England.

I look forward to reaching sixty next year, but I won't be retiring...like the man said...there are places to visit, people to meet and hobbies to enjoy!

Jean Ferridge

Jean Ferridge is the lady whose letter was published in the last issue of Tidings. She wrote to ask if there were any readers who had undergone a pelvic exenteration as she would like to correspond, or have a chat, with others who have had a similar operation. Six "exenterists" replied and we have passed their details on to Jean. Here is one of their letters...

Dear Editor

After reading the letter about pelvic exenteration in your autumn issue I thought I would write about my experience of that operation. In 2000 I was operated on for ovarian cancer and had six months of chemotherapy. In 2002 I needed more chemotherapy for a tumour low down on my colon. My colostomy was formed in 2004 as the tumor was blocking my bowel.

Adapting to life with a colostomy was a lot easier than I had thought, but the tumor was causing leakage from my anus. This was temporarily stopped by radiotherapy. My surgeon said he couldn't remove the tumour because it was a potentially life-threatening operation and would probably not be worthwhile because ovarian cancer tends to keep coming back.

In 2006 I had increased anal leakage and life was pretty miserable, but the tumour had only grown a small amount and there was no new tumour. Anyway I was offered an exenteration-pelvic clearance. Three surgeons operated on me and removed the tumour, the rectum, the bladder, and anything else left in there! I am now cancer-free for the first time in seven years even though I have to manage two bags. It has taken six months to feel okay but now I am able to live a relatively normal life.

Yours sincerely
V. R. (Mrs)

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 22nd February 2008 will be considered for inclusion in the next issue of Tidings.

Holiday Apartment within fellow Colostomates home

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For more details ring: 01548 581163

Have you any old toys in your house that you no longer want?

I am interested in diecast cars/trains/planes etc. Items will be sold at Toy Fairs or on E-bay and a proportion of the proceeds will go to the Colostomy Association

Please contact 07748 077162

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

Visit our website www.colostomyassociation.org.uk

Open Days..

Gill and Jeanette, the stoma care nurses from **The Queen Elizabeth Hospital King's Lynn,** are organising a Stoma Care Open Day.

Date: Sat 2nd February 2008.
Time 10am and 4pm.
Venue: Knights Hill Hotel,
South Wootton,
Kings's Lynn, Norfolk.

The **colorectal nurse specialists** at **The John Radcliff Hospital, Oxford** are holding a Stomatherapy Patient Open Day.

Date: Sat 5th April 2008.
Time: 10am – 2pm.
Venue: Academic Street Foyer
Level 3
John Radcliffe Hospital.

Walsall Hospital is holding a **Bowel Awareness Open day**, a health promotion event designed to raise public awareness of bowel disease.

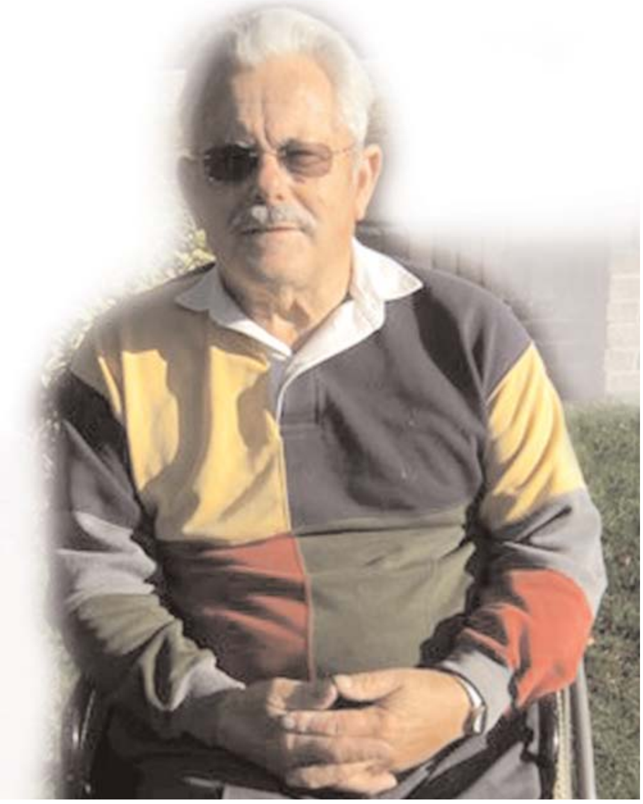
Date: Wed 16th April 2008
Time: 12 noon – 4pm.
Venue: Upper Room
The Crossing at St Paul's,
Darwall Street
Walsall WS1 1DA

Stoma Care Open Days organised by nurses working within the NHS, where several manufacturers and suppliers are represented, will be included on this page free of charge.

Tidings

Dedicated to Colostomates and their Carers

Coping with a colostomy... and spinal injury



I am a paraplegic with full upper body movement but completely paralysed below the waist and with no feeling below that level. I rise each morning by sliding from bed to wheelchair, or perhaps a shower chair, and the rest of the day is spent doing things on four wheels. Please note we don't say 'wheelchair bound' as this term is a contradiction of facts - without our wheels we would be confined to a bed or an armchair, so our wheelchairs give us the freedom to move about and live as normally as possible.

When my colostomy pouch needs changing I make sure everything is at hand: towel, colostomy items, container for disposables etc. The process involves partially undressing, removing the pouch for disposal, cleaning around the stoma, drying off and applying the new pouch, and finally dressing again. I suppose this is exactly what able-bodied colostomates do and even though one is in a seated position it usually takes only five minutes. This is one of the chief advantages in having a colostomy. People with no sensation below the waist have very little idea of what is happening when seated on a toilet during normal bowel functioning, and manual evacuation over a long period can result in dreadful complications as I know to my cost.

However, spinally injured colostomates have to be extra wary of skin damage because they may be unable to feel any discomfort around the stoma. Red areas, sore looking patches or skin lesions have to be carefully attended to because neglect can result in open weeping wounds. Another problem that might arise for a seated person with a large abdomen is how to obtain a view of the stoma area. This can sometimes be solved by deftly working with both hands and perhaps a mirror, the only alternative being to transfer to a bed and deal with things in a semi-reclined position which is much less convenient.

In Britain there is an increasing awareness about access for disabled people, and none is more important than accessible toilets in public areas. But this is not the case everywhere and a serious concern for the "non ambulant" colostomate arises on long haul air travel. Someone who can only reach an aircraft toilet by being pushed along the aisle in a transporter chair is faced with an immediate problem because not all aircraft provide this item of equipment. A second difficulty then arises because the toilet area is usually not large enough for the door to be closed. Last year I narrowly escaped being embarrassed when booking an expensive holiday with a well known tour company. On discovering our return journey would involve a fifteen hour flight we inquired how I would reach the toilet and were told my wife would have to carry me. We cancelled immediately and were given a full refund.

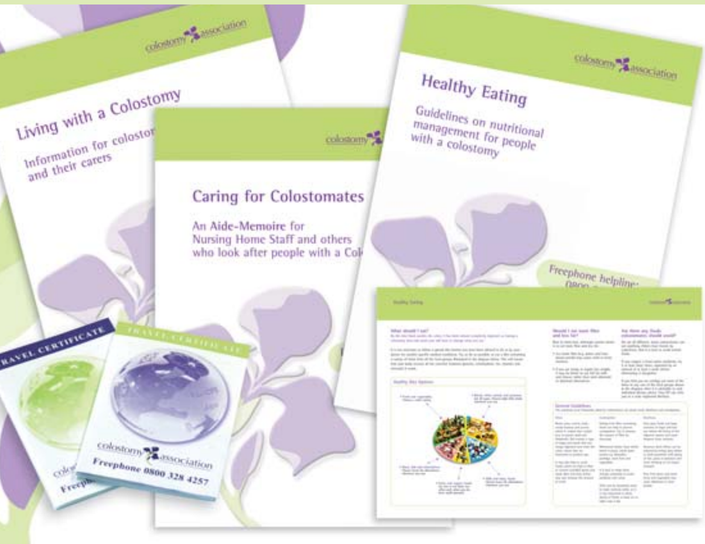
A much more frequent problem for colostomates who are unable to stand up arises when travelling by car. Transferring from a wheelchair to a car seat involves crossing a gap, and various techniques are employed all of which need good arm and shoulder strength. This sideways movement invariably causes ones clothing to drag or twist and the part that takes the strain is the waist belt which, as we all know, lies across the colostomy pouch. Pulling and dragging on the pouch can have disastrous results but I have not yet come across a solution to this problem apart from wearing braces. Also I would be glad of advice on how to check if everything is OK before it is too late when seated in a car with other people present.

Spinally injured people will of course receive all the information they need from their stoma care nurses but this will never fill the gap in their confidence, a gap that can only be filled by sharing the experience with someone who is in the same situation. I shall never forget that young wheelchair athlete in Stoke Mandeville Hospital who paused at my bedside when I was recovering from my disastrous accident – he put his hand on my useless legs and said, 'Don't worry mate, you'll soon be enjoying what I'm doing.' That was worth more than anything the doctors told me because I believed him. We need realistic, similar role models. Coping with a colostomy is quite similar to how we learned to handle our disability - with a quiet determination to get it right. At first it may seem an overwhelming burden but it will become easier in due course. I well remember the old fashioned strict regime in the spinal injuries rehabilitation hospital I first attended over thirty years ago – 'It's your disability, so just learn to live with it'.

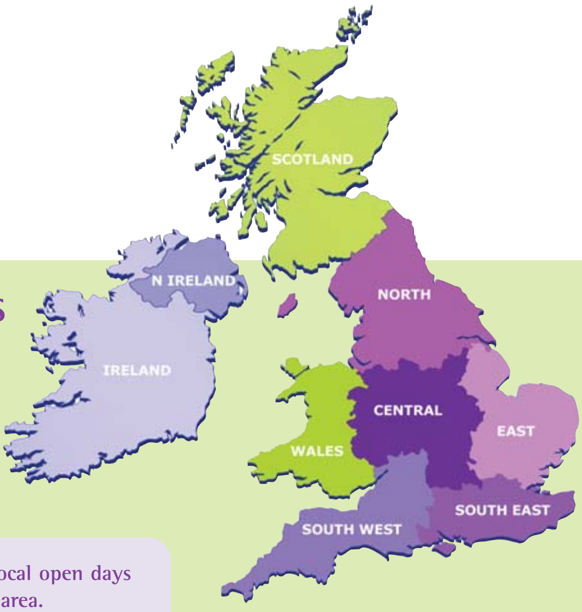
One reads of able bodied colostomates inquiring about reversals suggesting that they would be happier if they were able to return to their original "normal" state. The opposite is true in my case because having a colostomy has made my life much easier and safer and as soon as I realised this I arranged for it to be made permanent. When I pointed this out to my spinal injuries consultant he wholeheartedly agreed I had done the right thing. He regretted that most of his wheelchair patients would not consider having a colostomy because it would push them even further away from what they considered to be normal. How true is the saying "you can lead a horse to water..."?

Ken Roberts

New Literature...



- **Living with a Colostomy**
  A 32 page booklet for new colostomates
- **Caring for Colostomates**
  An aide-memoire for nursing home staff and others who look after people with a colostomy
- **Travel Advice**
- **Healthy Eating**
- **An Introduction to Irrigation**



and a warm welcome to our New Volunteers

The Colostomy Association welcomes new volunteers in the following areas:

Cumbria: Sue Hanhan	West Midlands: Mike Tomkins	South Yorkshire: Karen Kilford
Gloucestershire: Yvonne Penfold	Oxfordshire: Janet Bradley, Ken Hill	South Wales: David Ford
London: Julian Sayers		

Our new volunteers will be manning the CA stand at local open days and will also be happy to visit new ostomates in their area.

Moving on...

Doreen on her ascent of Dobratsch near the Austrian/Slovenian Border during the holiday she could not have contemplated eighteen months ago. Doreen says, 'I felt I had climbed a mountain in more ways than one!'

Doreen Littlewood records her experiences over the last few years - first an ileostomy, then a colo-anal pouch and finally a colostomy. She says, 'A bonus for me in writing this diary was that I have found it a cathartic experience and it has helped me to realise just how far I have come.'

September 2004

I was diagnosed with colo-rectal cancer and was admitted to hospital for an anterior re-section of the colon which necessitated a temporary ileostomy. Re-section of the colon was lower than anticipated which left me with virtually no rectum. Therefore, an internal colo-anal pouch was created to compensate. Thankfully, the cancer was removed and no further treatment was necessary, but my recovery was not straightforward. It wasn't until February 2005 that I felt well enough to have the reversal of the ileostomy my consultant had previously planned.

February 2005

The ileostomy was reversed and that is when my problems really started! I was told that my bowel movements would be frequent and unpredictable, but this would settle down to possibly between four and eight times per day. This I could have accepted as the price to pay for having the cancerous growth removed. However, I was totally unprepared for what happened after every time I ate: up to sixteen bowel movements over a period of up to three hours, regardless of what I did or didn't eat, how much or how little and when. Neither was I prepared for the extreme inflammation, pain and discomfort in the anal area, nor the incontinence. I kept a comprehensive diary of what and when I ate and of bowel movements to see if it was certain foods causing the problems. No pattern seemed to emerge. Various medications were tried including Loperamide and Mebeverine, but they caused even more discomfort and pain.

I was given various contradictory advice: I was told that it could take up to six months to settle down to an acceptable level, then I was told that it could be twelve months and then I was told that maybe it never would. It was suggested that due to the surgery my anal sphincter muscle function was poor, but that any intervention was unlikely to improve it. I myself felt that the internal colo-anal pouch was not functioning as it should and did not have the extra capacity required.

During the twelve months I had the colo-anal pouch, apart from the misery and physical discomfort and incontinence problems I was experiencing, my social life and quality of life took a nose dive. I was unable to go out with my husband for a meal or enjoy a meal at other people's houses because of the consequences. Peter and I had always loved hill walking and also bike rides and would pack up a picnic lunch or have a pub lunch en route. This was no longer possible unless I had a very early light breakfast and waited two or three hours before going out. I then had to walk all day without taking any refreshment until I got home in the evening and then paid the price. Hotel holidays were out of the question.

Every time I saw my consultant I kept getting contradictory information. I felt he thought I was exaggerating. At one point he told me that he thought a permanent colostomy would perhaps be the way back to quality of life. He could do one that summer, but I would need to go away and think very carefully about it. I did my research and spoke to people who had undergone and lived with a colostomy. However, when I saw him a few weeks later he told me he 'wouldn't want to do one at this stage!'

March 2006

After twelve months of sheer misery, physical discomfort and incontinence, I asked to be referred to another colo-rectal surgeon who said that if there had been no significant improvement after this length of time it was unlikely there would be much further improvement. We discussed the possibility of a colostomy and he emphasised the problems I might possibly experience but said that he would like to do his own assessment before going ahead. This included a gastroscopy, a flexible sigmoidoscopy and a barium X-ray, the result of which showed that I had a much faster throughput from the small bowel to the large bowel than normal. I said that this had never been the case before surgery so why now? He said that it had probably been like it all my life but my system had been able to cope with it until I had surgery.

July 2006

The decision was made to go ahead with a colostomy and in July 2006 I had surgery. In less than a week I was eating and able to enjoy meals without the consequences. My family and friends were amazed at how quickly I recovered. My stoma nurse was excellent and very supportive as was my husband, Peter, who has been a tower of strength since my diagnosis and throughout my ordeal.

September 2006

My recovery was such that six weeks later Peter and I were able to holiday in our caravan and walk the Yorkshire Dales, and, yes, I was able to eat a packed lunch as well as meals out without consequences. I was coping with all the practicalities of managing a colostomy and none of the potential problems I had been warned about (e.g. phantom pain) materialised.

November 2006

November saw us on holiday in the Lake District and I climbed Skiddaw and Blencathra, did an eleven and a half mile circular walk and even went swimming having been provided with the appropriate stoma appliance and a stoma friendly swimsuit (stylish, not frumpy!).

January 2007

Another holiday: this time in Cornwall walking the coastal footpath. Started swimming at 8.00am, three times per week!

March 2007

Then the big challenge – taking a holiday abroad! How would I cope with the flight and cabin pressure affecting my pouch, taking my supplies with me, disposal problems at hotels, medical insurance cover etc? I spoke to a very friendly lady called Jackie at the Colostomy Association who gave me lots of helpful advice and tips, together with a list of medical insurance companies willing to cover my condition and a travel certificate explaining the medical supplies in my hand luggage for airport security. We spent ten days in Austria – no, not skiing, but we did take our walking boots and had a fantastic climb up Dobratsch (2,166m high near the Austrian/Slovenian border – a mountain I felt I had climbed in more ways than one!). We also enjoyed many other activities and all my anxieties were unfounded.

April 2007

Reached thirty lengths per session swimming three times per week. Also did my first bike ride since surgery.

Finally

Out of choice I wouldn't choose to live with a colostomy and it is not without its minor problems and discomforts, which can become major if I allow them to. However, it is nothing compared to the previous daily physical discomfort, pain and resulting stress. I have re-gained quality of life, have been able to resume my social life and can now do all the activities which Peter and I so loved doing together prior to the initial surgery. I have a greater awareness of being and feeling "alive" even if I am approaching sixty-two years old. There is plenty more life in me yet!

Doreen Littlewood

Ken's Poem

Nine years ago to be precise,
A surgeon put me in a coma.
Lo and behold when I came round,
I found I had a stoma.
So I don't sit on the toilet now,
It all goes in a bag.
An excellent arrangement,
But now and again there's a snag.
Sometimes it tends to pancake,
And sometimes it balloons,
And though you may not think so,
It can also play little tunes!
Another little problem,
About which I prefer not to speak,
Is that suddenly without warning,
The darn thing can develop a leak.
The credit side to all of this,
Is that I still have a life.
For this I must be grateful,
To my ever loving wife.
This is something I must say
And think everyone should know,
She sent me to the doctors,
When I didn't want to go.
I should have seen the warning signs
Eight stone instead of eleven,
It's obvious now on looking back,
I was on my way to heaven.
(Or that other place!)
I've made a good recovery
That's the name of the game,
So to anyone who is in the same boat,
Take heart you can do the same.
So raise a glass and drink a toast,
To the years which lie ahead,
For one thing is certain in this life,
You're a long time dead.

Kenneth Williams

Kenneth says, 'I was seventy-five when I had my colostomy operation. I am now almost eighty-four and still going!'

Dear Nurse...

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

Q: *I am troubled by odour. I change my pouch every evening before bed and use a lubricant/deodorant inside the new pouch. By mid-morning the odour develops. I have tried bags with and without filters. I have tried the clamp-type and closed-end bags. There is no evident leakage from the pouch or skin barrier. I would appreciate any salient advice. Thank you.*

A: Odours may originate from either your diet or medication. Certain foods for instance onions, spicy foods or green vegetables may cause an odour with certain individuals. However, not everyone is the same and therefore it may be beneficial to keep a food diary for a short while, noting what foods you eat and when you feel there is an odour. Also it may be worth speaking to your GP to discuss if any regular medication you take is the source of the problem. He may then be able to give you an alternative to try.

There does not appear to be any physical cause for the odours as you state there is no leakage from the pouch or skin barrier. However, you do not state if the odours are noticed by anyone else. You could ask your close family if they have noticed anything. It may be that you are more sensitive to the possibility of odours and are therefore more likely to notice them. If this is the case you may find the use of perfume or aftershave placed on the cover of the pouch will disguise the odour and make you feel more comfortable.

Q: *A close friend of mine has just undergone a stoma reversal operation after having a colostomy for almost a year. He is seventy-four and unsure of what to expect after the operation. I can't find much useful information on the net. He has been given no after-care advice from the hospital and needs to know about diet and any problems he may experience regarding bowel movements and pain in these first few weeks. How long it will be before he is back to normal, if ever?*

A: Most patients having reversal of a colostomy recover very well from surgery and return to their usual lifestyle in a relatively short period of time. It is difficult to say how long it will take for the gentleman to recover from surgery as you do not say whether the reversal involved opening the previous abdominal scar. If he underwent a laparotomy (opening of the previous wound) to enable reversal of the stoma it will be approximately six weeks before he can drive and eight to twelve weeks before he is able to do any lifting such as carrying heavy shopping or strenuous work like gardening or cleaning windows. If however it was done via the stoma wound only, then he will recover a lot faster.

He may find his bowel movements are a little erratic to start with and the output may be looser than previously. However, depending on how much bowel was removed during the original operation, his bowel action should return to a regular pattern. With regard to diet he should be able to eat normally, although it may be worth building up to a normal diet slowly.

I hope this is useful but if your friend requires any more in-depth detail specific to his surgery it would be beneficial to contact his stoma care nurse.

Q: *I was just wondering if you could help. My dad has to have an operation to dilate his stoma as it has retracted. Could you tell me more about this operation? Why do things like a retracted stoma and stoma closing happen?*

A: A stoma usually closes or restricts due to an initial problem with healing immediately after surgery. Quite often this will heal without any further problems but on occasions the new tissue will continue to form causing the stoma to tighten. If this happens then it is possible in the short term to dilate the stoma using a special dilator. An ostomate can be taught how to do this or if it is very tight it can be carried out under a light anaesthetic.

However, eventually surgery may be required to refashion the stoma. This may involve a laparotomy (opening up the old scar in the tummy) or may be done as a local procedure where the stoma is released from the skin edge and a new piece of bowel pulled to the surface. Alternatively, if the stoma is only temporary then the stoma will be reversed as soon as is possible with dilation keeping the stoma open in the short term.

Without more detailed information regarding your dad's previous surgery I am unable to answer the specifics and it may be worth speaking to the local stoma care nurse, who will have access to the medical notes, or to the surgeon doing the procedure.

Q: *I am writing this letter on behalf of my wife. She had a colostomy done in April after an emergency operation back in 2001. Because it was an emergency the result is she suffers constant pain in the back passage which the hospital has tried to cure with injections on many occasions, but with no results. I would like to know if any other ostomates have the same problems. My wife gets too distressed to write herself hence I am doing it for her.*

Dear Nurse...

A: Occasionally ostomates do have this problem which once investigated is not due to any physical cause but often the result of a nerve problem. These can be difficult to treat or manage and often require referral to a chronic pain consultant. If your wife has been investigated and does not have any obvious cause for this distressing problem it may be worth asking for her to be referred to your local pain consultant to see if they can provide any relief for her.

Q: My father has a problem with detachment of his stoma bag. He has a large hernia which is causing problems keeping the bags in place. His surgeon is reluctant to repair the hernia and/or reverse the ileostomy so it looks like he has to put up with the bag problem. I wondered if you could give any advice.

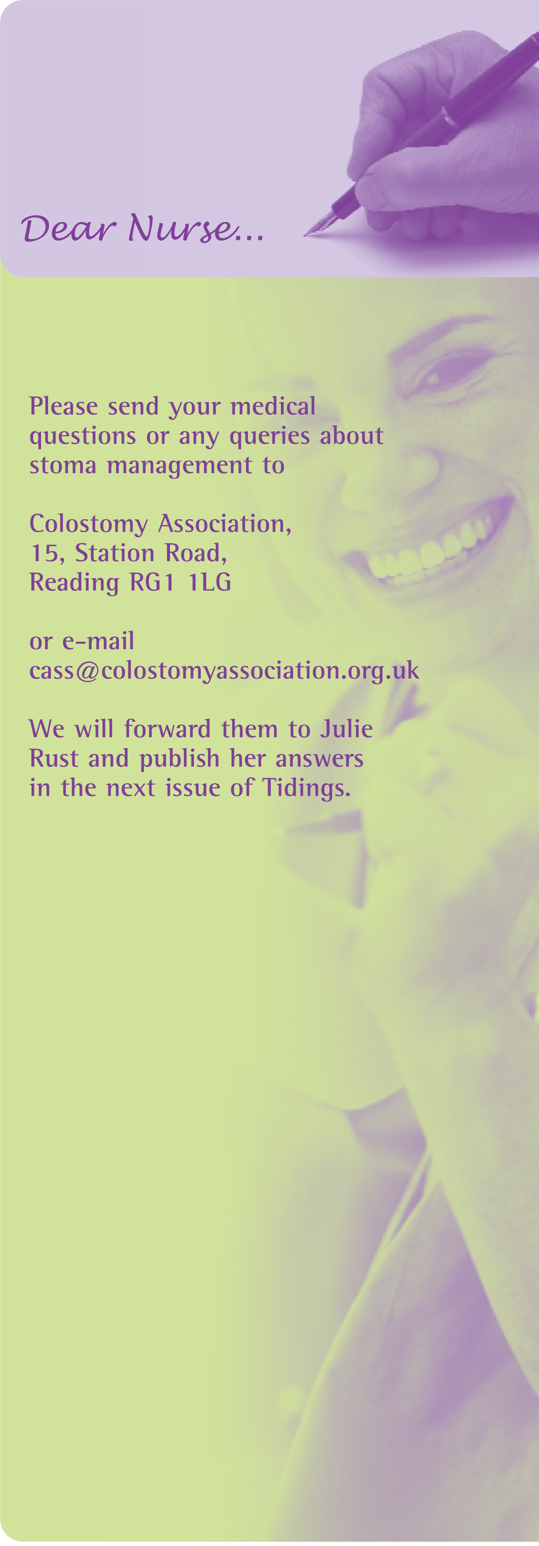
A: The use of an abdominal support is often recommended if a hernia is unable to be repaired surgically and therefore it may be worth asking for a review by the stoma care team. They may be able to either measure your father for an abdominal support themselves or refer him to one of the many companies who offer this service. As for the problem with the adhesion of the pouch due to the shape of the hernia there are now special pouches made for this purpose and again the stoma care nurses should be able to advise.

Q: I had my colostomy in February 2006. I use a two-piece pouch because I found the one-piece impossible as I kept having leaks. I have adjusted to my colostomy very well, I think, but I have always suffered from pancaking, despite numerous efforts to combat the problem. So I have learned to cope with it.

My problem is that I have suddenly started suffering a lot of soreness and discomfort around my base-plate – not on the inside near the stoma but at the outer edge. I do get some problems with soreness around my stoma but I use a barrier cream for that. However, I cannot use this as my base-plate will not stick. This reaction has only just started but I have not been using anything different on my skin.
I do get allergic reactions to metal and occasionally have had a bit of a flare up from the tape hospitals use to keep drips in place.

Is there anything I can use to protect my skin that won't stop the base-plate from sticking? I would be very grateful for any help you or other colostomates could give.

A: There are many reasons for soreness around the site of the stoma, allergy to the adhesive being one of them. A review by your stoma care nurse would identify if the problems you are describing is a true allergy, in which case a change of product would be beneficial. The stoma care nurse would be able to advise you on which products would be suitable, bearing in mind you prefer a two piece appliance. If the soreness is not due to an allergy there are many products on the market which could help relieve this problem and again your stoma care nurse can advise. Barrier creams made specifically for use with stoma pouches are available and if used sparingly, rubbed well in and any excess wiped off with a dry tissue may help the soreness without causing a problem with adhesion of the pouch.

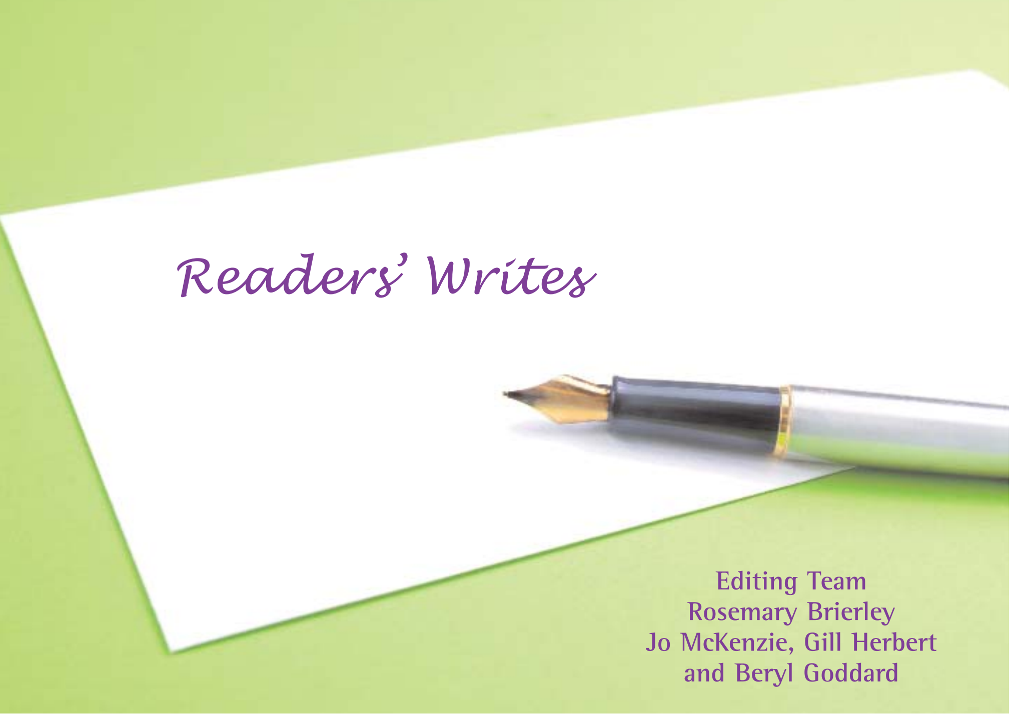


Please send your medical questions or any queries about stoma management to

Colostomy Association,
15, Station Road,
Reading RG1 1LG

or e-mail
cass@colostomyassociation.org.uk

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



Readers' Writes

Dear Editor

I had my operation for a blockage in the bowel in July 2003 and received prompt medical attention here in North Wales. I was admitted to hospital by ambulance and told that I would need an emergency operation – a life or death situation. I had no time to make any decision.

I had the operation on the following morning and that evening my husband visited me and neither he nor I knew that I had a colostomy. It was a great shock to learn three days later that I had a bag. Unfortunately circumstances had warranted this - I was told later at home that I had a Dukes 'B' cancer.

I was very fortunate that everything went well and I did not need chemotherapy. I am seventy-three years old now and have a hernia, a permanent colostomy, osteoporosis, osteoarthritis and have had a kidney removed.

I thank God for each day and I feel very grateful for the help of my husband and family. I also appreciate the help the doctors and nurses gave me in hospital and the care I have been given since. My motto is "Never give up".

Many thanks for all the useful information in your magazine which I read avidly and I know that many people are much worse off.

Yours sincerely
J. W. (Mrs)

Dear Editor

There's no substitute for a good euphemism, is there? Phantom rectal pain is well known, and much has been said about it, but I would like to bring to your notice an entirely different effect, which arises as a consequence of the use of pre-operative high dose radiotherapy in cases of anal and ano-rectal cancer. This is becoming less common, now that efficient scanning techniques are available to determine the margins of the cancer, so that it can reliably be completely removed by surgery. Nine years ago, when I had my surgery, radiotherapy was the standard procedure. After no more than a couple of treatments I felt fine: what had been a very uncomfortable condition no longer caused any discomfort, and I felt that I was already being cured. The effects only came to light later: a full six months for the perineal wound to heal (almost worse than the disease!) and almost complete erectile dysfunction.

It was not until about five years had passed that I began to feel that there was something wrong: in the perineal region there seemed to be more of me than there should be - had the cancer returned? I made an appointment to see my consultant, who after a very thorough examination assured me that everything was exactly as it ought to be, and I could be completely confident that there was nothing wrong. We discussed why I had been so convinced that there was a problem, and we came to the conclusion that the nerves which had been damaged by the radiotherapy were slowly growing back again. The "problem" had been that I could feel my bottom for the first time in five years! I still get the occasional feeling of something "different", but then I realise that this is how I ought to feel, and it seems quite normal again.

Perhaps, if someone else experiences a similar feeling, they can be assured that it does not necessarily mean that something is wrong, although it would be as well to get it checked.

Best regards,
Adrian March (CA Trustee)

Dear Editor

I had rectal cancer and was given a colostomy and mucus fistula operation in March 1998 – just three months before my retirement. During June and July I had extensive chemotherapy and radiotherapy. My follow-up check in November was quite a shock. My consultants exact words were: 'I've got some good news and some bad news. The good news is that the tumour has gone. The bad news is we have found a cancerous polyp in the back passage and you will have to have an operation to re-site the colostomy and remove your sigmoid colon, rectum and anus.

The dreaded day was arranged for December 31st 1998. After a five hour operation I went back on the ward. The next morning I was taken back into the operating theatre to have the packing in my behind changed. 'Happy New Year,' the surgeon said!

District nurses changed the packing every day for nine months until the wound closed up. It took longer as I had MRSA. After some early trouble with my stoma it settled down and I was able to live a fairly normal life, being able to have holidays in Memphis and Belguim.

Then in February 2005 I had a heart attack and had a stent fitted. Although I am not able to exert myself I can still drive so we get out as much as possible.

Yours sincerely
C.O. (Mr)

Dear Editor

So many of the letters and articles in Tidings echo parts of my story. I was a first child, born in 1927. I think my problems stem from my mother's desire to do the best for me – as understood at that time. 'You were constipated from the day you were born,' she would say. "Regularity" was all and I was never regular. I was made to sit every day until I "performed" – often left for hours. I can still remember the agony of enemas – long black rubber tubes. I always suffered from constipation and feel it was due to this misguided regime. I took care never to ask any of my three children about their bowels and I don't think they ever had problems.

In my sixties I became faecally incontinent and after many investigations I had a colon resection. I try not to remember the nightmare months when, as a result of this, I spent hours on the loo and suffered severe stomach cramps. The only thing which gave me any relief at this time was a neat whisky. As I was at the time heavily involved in committee work trying to help people control excess alcohol use and abuse, this gave me some embarrassment. 'I only take sips,' I assured my doctor/surgeon/director. 'Ho, Ho, enjoy it,' they replied.

Eventually I gained some control via drugs, but for some time I had to resort to manual extraction with the aid of KY gel. In 2005 I experienced considerable pain and thought I had another prolapsed bowel. The consultant told me my sphincter had gone and I should have a colostomy. That night my supremely fit, active and caring husband, of fifty-three years, was taken ill. All my problems were on hold while he underwent chemotherapy and at Christmas 2005 he had surgery from which he did not recover.

Six weeks later I had a colostomy. When nothing appeared in the bag, further investigations discovered adhesions from an earlier operation and more surgery was needed. I spent four weeks in hospital. I gradually learnt to cope but began to have leaks. The stoma prolapsed and so I had another spell in hospital in October 2006.

At last I think we have found the right bag - a convex flange copes with the very deep "gully" on one side and I find a drainable bag much easier to deal with. For about three weeks now I have had no problem. Early morning I have a good shower and change the bag and then rest of the day I use public or private toilets just like (or about just like) anyone else.

I am now almost eighty and living on my own for the first time in my life. I find I have to take everything very slowly, but I hope now I can start to live again.

With all best wishes
P.M.N. (Mrs)

Dear Editor

I have had a colostomy and urostomy for sixteen years. I look after them myself even though I am not able to see well and my hands jerk as I have neurofibromatosis. To change the whole lot takes nearly three quarters of an hour. My district nurses have offered to help but I want to keep what little independence I have left. I'm rather disabled: my balance, hearing, speech and sight have all been affected.

The stomas were a must, or I wouldn't be in the land of the living. I've got no special names for them. Only when they leak, then I call them a lot of funny names! I have a fantastic stoma care sister. She is now retiring but she was always on hand when I first had my stomas and I would have been lost without her,

Thank you
B.T. (Mrs)

Dear Editor

I had my operation for a bowel abscess, apparently at the point of bursting, just over a year ago and ended up with a colostomy. I have suffered from rheumatoid arthritis for over thirty years and on waking from the operation I had not only to deal with the bag but also with the fact that I couldn't lift myself up from the pillow. I lay in bed virtually helpless for more than two weeks.

I had no incentive to help myself and my daughter started talking about putting me into a care home. This really shocked me out of my lethargy. Also my adorable six year old granddaughter would come up to my bed, hold my hand, stroke my forehead and occasionally lie next to me. She made me feel I had something to live for. So I managed to sit up, get out of bed and begin to walk again. After two months in hospital I was discharged and, with the help of my fantastic carers, started to live again.

I still suffer from an unpleasant vaginal discharge and also, as a result of what was apparently a massive operation, my drainage holes on the operation scar continue to leak. However, I am coping with these problems.

Yours very sincerely
J. M. (Mrs)

Dear Editor

I noticed that in the last issue of Tidings some people said they are wary of travelling by plane. I am eighty-four years old and for the last two and a half years have travelled by myself to see my family in Phoenix, Arizona, USA - a four hour journey to Heathrow by bus, and a ten hour flight. I have found the British Airways personnel most helpful at both airports and had no difficulty in dealing with my stoma – now over four years old.

I get insurance but there is a clause excluding my stoma - thank goodness I have had no difficulty. I travel twice a year in April and October. It's lovely to be with my family for three weeks and to see my first great grandson who was born in August last year. I trust I'll be able to go again in April this year.

Yours sincerely
E. J. (Mrs)

From Ed...

Dear All...

Thank you for your letters and e-mails. Please keep them coming and we will 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.

The North Notts Stoma Support Group

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.

Tidings
Dedicated to Colostomates and their Carers


Some members of the group and their families who enjoyed a session at Sutton-in Ashfield swimming baths in October 2007

The group has been in existence for approximately five years. We meet every second Saturday in the month from 10a.m. to 12noon at The New Boardroom, Kingsmill Hospital, Sutton-in-Ashfield.

Our aim is to encourage patients to overcome the trauma of their operations and to show what they are able to achieve in their lives such as travelling and eating out. We have arranged coach trips and hold swimming sessions twice a year.

In the past we have had guest speakers on topics such as aromatherapy and the Lincs/Notts Air ambulance service. The Nottinghamshire District Coroner also gave a very interesting talk. We hold very informal meetings where we discuss problems we have encountered and how to deal with them. Unfortunately for some time we haven't had the luxury of a qualified stoma nurse to give more medical advice. However, at a recent visit to Salts of Birmingham the problem of a lack of stoma nursing advice at our meetings was raised during a general discussion about support group activities. We have since learnt that Kate Howlett, a qualified stoma nurse, will be attending our monthly meetings.

Although the group is small it is hoped that with the help of the local stoma care nurses at Kings Mill Hospital, who will inform all new and existing patients about our group, we will thrive.

For more information
please contact:
Tore Norman 01773 715460

News of local stoma support groups...

The Glasgow Self-help Stoma Support Group,"Fittleworth Friends", meets at the Fittleworth Care Centre, Unit 1 Riverside Business Park, Moffat Street,Glasgow G5 0PD on the first Tuesday of every month at 10am.
Dates of next meetings:
5th February 2008
4th March 2008
(There will be no meeting in January in case of poor weather conditions and travelling difficulties)
For further details contact Maureen 0800 783 7148

Optomists, the Cornwall Ostomy Support Group, meets at the Headquarters of the Cornwall Women's Institute, Three Milestone, Truro Business Park, TR4 9NH, usually on the first Monday of the month from 2pm till 4pm
Dates of next meetings:
4th February 2008.
3rd March 2008
7th April 2008.
For further details contact Sue Hatton 01326 340058

Devon IA (supporting Devon and South Somerset) welcome anyone with a stoma to their meetings:
Umberleigh Village Hall, North Devon.
Thursday 6th March 2008 at 12 noon.

West Hill Village Hall, West Hill,
Ottery St Mary.
Saturday 12th April 2008 at 12 noon.

Display of stoma care products.
Refreshments.
For more information contact:
Margaret Bond (Secretary) 01392 447374 Bomarg10@aol.com

Essex Stoma Patients Support Group meets at St Catherines Church Hall, Southend Road, Wickford on the last Tuesday of the month from 7pm to 9pm.
Date of next meeting:
29th January 2008.
For further details contact Margaret Copsey 01268 271123

If you contact us before 22nd February 2008 we will publish the date and venue of your next Stoma Support Group meeting.

New Support Group in Southampton
Carole Summer, a colostomate who lives in Southampton, is setting up a local support group for people with stomas. She would like to hear from people who would be interested in attending monthly meetings.
If you live in the SO postcode area and would like to meet up with other ostomates contact Carole:
Tel No 02380 446 779
E-mail carole.lesley@btinternet.com

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.

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E-mail:______________________ Details of the current pouch you use: ☐ One piece ☐ Two piece

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Please send me: ☐ Drainable ☐ Closed
☐ Midi ☐ Maxi ☐ Maxi Plus

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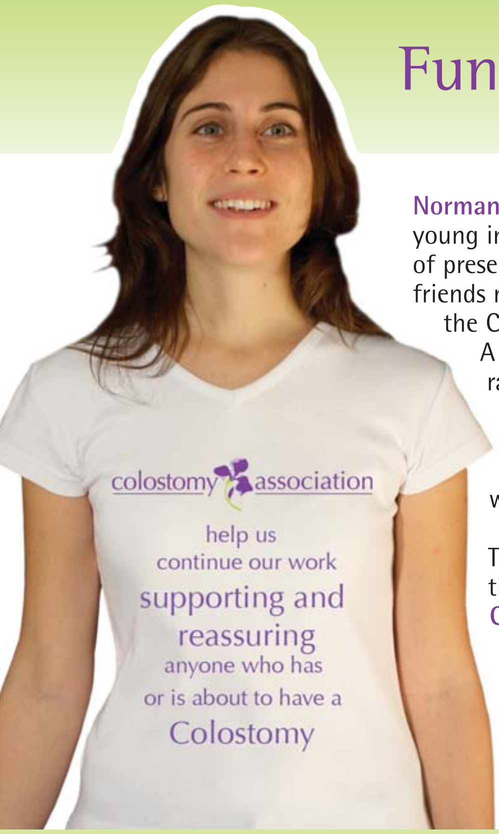

Fundraising...success

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

Norman Selwyn was 80 years young in August and instead of presents requested that friends made a donation to the Colostomy Association. A fantastic £345 was raised. We heard that Norman also received enough bottles of his favourite malt whisky to open a shop!

The veterans section of the **Lords Golf & Country Club** in Rayleigh, Essex held a charity golf day to support the association. This event raised £583.50.

Nikki Cameron of Glasgow held a "Dress down Friday" at work and sent us a cheque for £45.50.

Sister Angela Jeff and Sister Deborah Singleton of the Colo-rectal and Stoma Care Department at Macclesfield General Hospital raised £124.32 at an open day held in August.

Please keep fundraising for us as we rely totally on donations to keep up our work of giving support to colostomates. Every penny does count!

Recycling

Did you receive a new mobile phone this Christmas? Please remember us if you have an old one to recycle.

Just give us a call and we will send you a freepost envelope.

colostomy association

Legacies...another way to continue to support our work

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 continue to support colostomates throughout the UK.

This would involve adding a clause to your will or, if you already have one, the addition of a codicil. You will need to consult your solicitor in both cases to ensure that you do not invalidate your will.

A typical clause is set out below.

1 Legacy to Colostomy Association

1.1 I give [words] pounds (£[figures]) to the Colostomy Association Limited of Mill Cottage Polwheveral Constantine Falmouth Cornwall TR11 5RW (registered charity number 1113471) (the 'Charity') and I request the Charity but without imposing any binding trust or legal obligation to use the legacy for its general charitable purposes.

1.2 If at the date of my death the Charity is no longer in existence or is subject to a winding up order, [my Executors shall pay the legacy to such other charitable body or bodies having the same or similar objects as my Executors shall select] [the legacy shall lapse].

1.3 The receipt of the treasurer or other appropriate officer for the time being of the Charity [or of any substituted charity to which the legacy is paid under sub clause [1.2]] shall be a good discharge to my Executors].

colostomy association

Support us...please become a Friend of the Colostomy Association

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

With your help we really can make a difference...our findings show there are approximately 60,000 colostomates living in the UK and with over 6,400 permanent colostomy operations being performed each year - **we need to be here for them!**

Other ways we help... The Association continues to help colostomates who are experienced and those who are new to living with a colostomy. We produce a regular quarterly magazine called 'Tidings'. We have over seventy volunteers who are all colostomates willing to make personal visits to offer support. We provide informative literature, attend hospital open days, and offer a twenty-four hour helpline. Our web site is being developed to reflect all of the above and more! 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.

Donations... Single donations from individuals and fundraising events are always welcome and greatly appreciated. Your financial support has never been more important. With a continuing income and planned agenda, we can budget for, and carry out, the excellent work of the Colostomy Association.

Becoming a 'Friend'...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.

Please help us to reach out to them with support and encouragement

I want to become a '**Friend**':

☐ I enclose a cheque/postal order for £12.00 (made payable to Colostomy Association)

☐ 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)

Note: Please ensure that we have your full name, address and postal code

Office Address: 15 Station Road Reading RG1 1LG 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, 15 Station Road, Reading RG1 1LG

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: Colostomy Association 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:

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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.

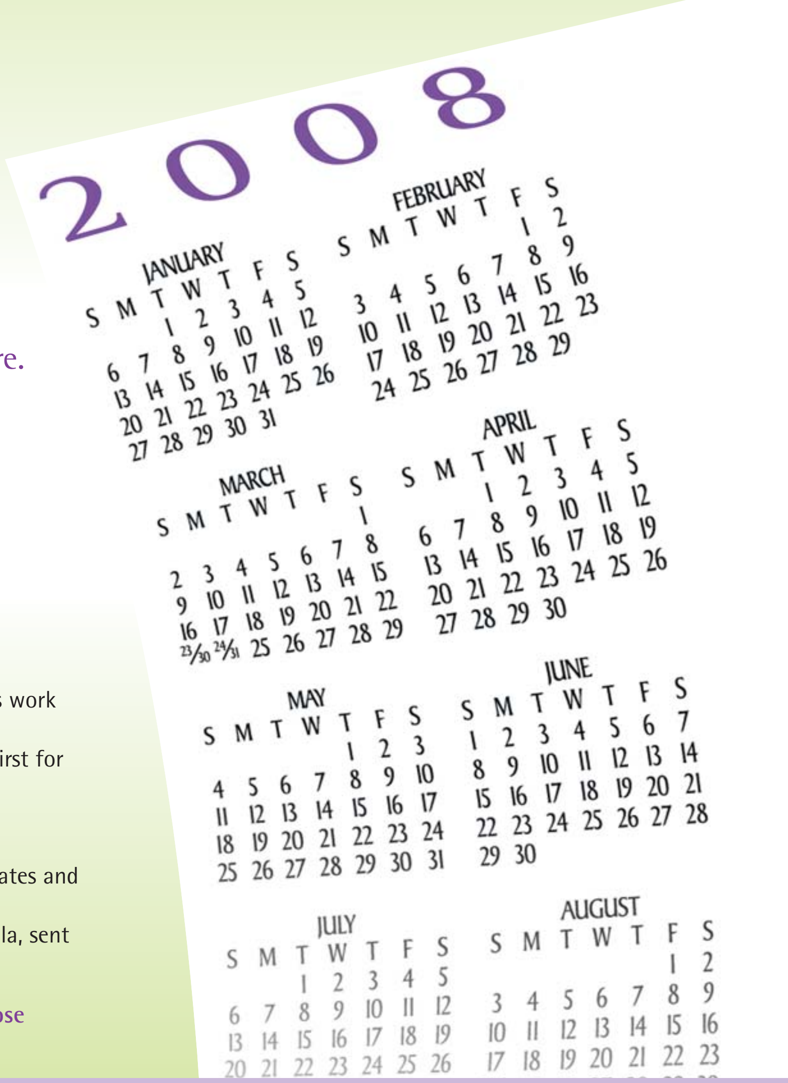
I confirm that I pay an amount of income tax and/or capital gains tax at least equal to the tax that the Colostomy Association reclaims on my donation in the appropriate year (currently 28p for every £1 donated).

Signed: Date:

colostomy association

We hope you all had a peaceful Christmas...with the start of a brand New Year, we would like to take this opportunity to thank all our readers, members and supporters for their help past, present and future.

We will continue to bring you Tidings and look forward to receiving your input and feedback, so we constantly keep improving your magazine...



Some sad news...During the last few months of 2007 we received the sad news that four of our volunteers had died.

John Isherwood became a volunteer for BCA in 1986 and continued his work supporting ostomates in the Manchester area when BCA became CA.
Geoff Newman from Cranleigh in Surrey became a volunteer in 2002, first for BCA then for CA.
Sheila Walker was one of the original Trustees when CA was formed in November 2006.
Sandy Wood from Perth became a volunteer in 2005 and visited ostomates and attended open days in the East of Scotland. At Sandy's funeral a collection was taken for the Colostomy Association and his wife, Sheila, sent a cheque for £200 as a donation to our funds.

The Colostomy Association sends sincere condolences to all those close to these most valued volunteers.

NEWS FLASH!

The new **FLEXIMATE** range of flanges from EuroTec brought to you by PEAKMEDICAL

Now, users of **COLOPLAST'S ASSURA*** range of products can enjoy the benefits of the most flexible skin barrier currently available.

Available in **40, 50 and 60mm** flange sizes and interchangeable with Coloplast's Assura two-piece ostomy system.

The Fleximate **SuperSoft flange** is considerably thicker and can therefore absorb more moisture, maintaining its integrity even in the warmest conditions. Softness, flexibility and comfort are achieved by the addition of a thin foam layer used to laminate the hydrocolloid skin barrier. This layer replaces the traditional potentially damaging layer of polyethylene film which has been known to cause lacerations and ulceration of the stoma. This does **not** occur with the Fleximate SuperSoft range of flanges!

The Fleximate **SoftFlex Flange** has all the features of **SuperSoft**, including the integral foam layer welded to the gasket of the hydrocolloid skin barrier by a revolutionary ultrasonic welding process. The closed cell structure of the foam layer prevents absorption of moisture and potential damage to the peristomal skin. The addition of a beige, flexible non-woven, hypoallergenic adhesive surround provides further comfort and peace of mind.

Fleximate **Convex and Extra Convex Flange** offer Coloplast Assura users the same softness an flexibility of the SuperSoft and SoftFlex product Each flange incorporates a skin friendly hydrocollo skin barrier over its entire surface and is laminate with the same soft and flexible upper layer polymeric foam. Available in two options, convex an extra convex and will fit 40, 50 and 60mm Assu two-piece pouches.

INFORMATION AND SAMPLE REQUEST SLIP:

Fleximate SuperSoft - starter hole flange size: 40mm [ ] 50mm [ ] 60mm [ ] (please tick)
Fleximate SoftFlex - starter hole flange size: 40mm [ ] 50mm [ ] 60mm [ ] (please tick)
Fleximate Convex - starter hole flange size: 40mm [ ] 50mm [ ] 60mm [ ] (please tick)
Fleximate Extra Convex - starter hole flange size: 40mm [ ] 50mm [ ] 60mm [ ] (please tick)

Stoma Size:
................mm

Name...Mr/Mrs/Miss/Ms
Address ....
....
....
Post code.............................Tel...

Call **Freephone 0800 652 0424** for an immediate response or post to:
Peak Medical, Holywell House Annexe, Holywell Street, Chesterfield S41 7SH

EuroTec From PEAKMEDICAL

*Coloplast Assura is a registered trademark of Coloplast A/S Denma
Convex products should be used with care and upon the advice a guidance of a specialist stoma care nurse.

Upfront

Out of Hours Telephone Helpline Service

Did you know that the CA Freephone Helpline is manned during the evening and at weekends?

When our head office closes at 5pm all our 0800 328 4257 calls are transferred to a team of thirteen volunteers throughout the country. All these volunteers have successfully completed the Telephone Helplines Association training courses. They all have a colostomy themselves therefore know what it's like to live with a stoma and are able to provide practical help, support and reassurance. However, the advice given is strictly non-medical.

Out of hours our volunteers answer the calls from their own homes. On rare occasions a volunteer may be unable to take your call immediately. Should this happen, please leave your name and number and the volunteer will phone you back. If possible could routine calls or those requesting literature be made on a weekday between 9am. & 5pm.

So remember, if you are a new ostomate or are finding it difficult to cope with your stoma and feel that speaking to someone else who also has a colostomy might help, ring 0800 328 4257.

Update on CATIP

The Colostomy Association Travel Insurance Policy (CATIP) has now been in place for nearly five months and we are issuing about fourteen policies each month. Commission earned by the association for the first four months of operation amounts to £265.

Based on feedback received, we feel that there is a need to clarify the details of the "special" arrangement relating to ostomates which has been agreed with the insurers. A colostomy, ileostomy or urostomy alone if it was formed more than two years prior to the commencement of cover under the policy does not constitute a "pre-existing" condition and does not need to be referred to the insurers. Hopefully this will enable more of our readers to benefit from the preferential rates that the insurance company are able to provide.

If you would like more information, and a quotation, please visit our website:-
www.colostomyassociation.org.uk
and click on the travel insurance link.

Tidings

Dedicated to Colostomates and their Carers

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.

Tidings is your Magazine

If you have a story, article, letter or any other item you would like to be included, please post them to The Editor. Alternatively e-mail to our contact details below. We look forward to hearing from you and will do our best to include your contributions.

Colostomy Association
15 Station Road
Reading RG1 1LG
Tel: 0118 939 1537
Freephone: 0800 328 4257
E-mail: cass@colostomyassociation.org.uk

Visit our web site

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
- **National Advisory Service for Parents of Children with a Stoma**
  Tel: 01560 322 024
  www.naspcs.co.uk
- **IOA International Ostomy Association**
  www.ostomyinternational.org
- **Gay Ostomates Website**
  e-mail info@gayostomates.org
  www.gayostomates.org

Support Organisations for medical conditions...

- **Macmillan Cancer Support**
  Tel: Switchboard 0207 840 7840
  Freephone:
  CancerLine: 0808 808 2020
  YouthLine: 0808 808 0800
  www.macmillan.org.uk
- **Cancerbackup**
  Freephone: 0808 800 1234
  www.cancerbackup.org.uk
- **National Association for Colitis and Crohn's disease**
  Tel: 0845 130 2233
  www.nacc.org.uk
- **The Gut Trust (Irritable bowel syndrome)**
  Tel: 0114 272 3253
  www.theguttrust.org
- **Incontact (Incontinence & Diverticular disease)**
  Tel: 0870 770 3246
  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).