

Roar!



Issue number 19 • New Year 2001

Roar! is the newsletter of the Red Lion Group • St. Mark's Hospital • Watford Road • Harrow • Middlesex • HA1 3UJ

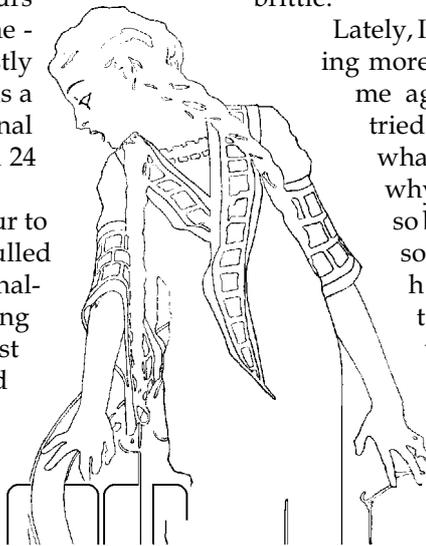
Gutsy to Gutless in 24 Hours

Susan Walls recalls how messing with her body also messed with her mind...

When I lost my guts, I lost my guts. Having a colectomy changed my personality overnight. Even during my last few hours with a colon I was still me - usually cheerful and mostly optimistic. Next day I was a hopeless, fearful, emotional mess. Gutsy to gutless in 24 hours. It was that fast.

For ages it didn't occur to me that someone had pulled the plug out of my personality, I was too busy being sorry for myself. For at least three years, I felt jagged round the edges; often depressed and always scared. Everything was going to hurt me: every car that passed was surely going to hurtle off course and crush me to death. It was ridiculous, and I knew it, and what's more it was ungrateful - people snatched from jaws of serious illness are sup-

posed to feel energised, in a glad-to-be-alive-every-day-is-wonderful sort of way. But I just felt flat and brittle.



Lately, I've been feeling more like the old me again, so I've tried to work out what happened: why did I crash so badly and for so long? It may have something to do with the fact that I felt so mutilated by surgery. Throughout the operations I

kept a diary of what happened and how I felt. Last week I read it for the first time in five years. This is the entry for four days after the operation; the day when I knew I had to look at myself for the first time:

"Today the stoma nurse is going to help me change the bag, so I'm going to have to confront the stoma. I've been feeling terrified all day. When she finally appears, she takes me into the treatment room and begins to assemble the ostomist's paraphernalia: bowl of warm water; scented disposal bag; wipes; and new stoma bag and clip. It all looks so terribly clinical. I feel really sick, and I want to run away again, but I don't want to look stupid in front of this good woman, so I stand my ground and start to shake instead. She's sympathetic, but matter of fact. The bag has to come off, and I've got to be involved in the process. This is my new body and I had better get used to it.

I look straight ahead at an interesting mark on the wall, while she peels off the sticky circle which attaches the bag to my stomach. She says something about how important it is to clean the skin around the stoma because the enzymes it produces can burn the skin. Then comes the kicker - she wants me to clean it. I really am going to have to look.

It's horrible. My trunk looks like a battle zone. There's an ugly scar running from about 10cm under my breastbone down to my pubic bone. On the right side of that, as I look down, is the stoma. It's gross, it looks like a large, red, wrinkled, angry-looking plum sticking out of the white skin of my stomach. As I watch, horrified, it squirts some goo out of its opening, like some disgusting alien. I thought I was prepared for how it would look, but

Day in the Sun

We look forward to welcoming you to the Red Lion Group 2001 Information Day and AGM to be held on 7 April 2001 at St Marks Hospital. A full programme and invitation will be issued shortly.

Reduced rate parking is once again available using pre-purchased tickets. Please send an SAE to David Irving-James with a cheque for £2 made payable to FMG. David's address is:

6 Gloster Close
Hawkinge
Folkestone
Kent
CT18 7PP

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nothing could have prepared me for this. I am poleaxed by the shock of coming face to face with it. Waves of pity hit me: not self-pity, but pity for my poor body, which is a quite different thing. To my eternal shame, I start to cry in huge sobs and the stoma nurse is left to clean up and attach the new bag."

Reading that now, it all seems terribly pathetic, but it was real enough at the time, and the shock waves took a long time to die down. I guess the only way through such an experience is to go so far down into yourself, that it's hard to get back up again.

Anyway, we lived like that for six months, the loathsome thing and I, and it didn't get any better. Physically, I was blooming - getting rid of five foot of suppurating pus from my pelvic region was a good move. But my head was in a bad way. I tried to be positive - I'd thumb through the Ileostomy Association Journal, looking for ways to cope, but all I found were articles from bubbly people who called their ileostomy cute things like "Vera The Volcano". I was not in the mood to name mine. I often dreamed that I had an overflow pipe sticking out of my stomach, and sewage was pouring out of it.

And strangely, things didn't get any better when the innards went back in again, where they belonged. After closure, I expected that good-to-be-alive feeling to kick in, but still things seemed grey and flat and I still felt jagged inside. Every time I had a flare-up of pouchitis (and there were many), I'd think: that's it, I'm going to lose the pouch and I'll have to have the loathsome thing back, forever this time.

But gradually, my state of mind did improve. I can't say when, because it took a while to notice that I was having fun again. I still get bad times - recently I had bleeding with a flare-up of pouchitis which scared me more than I can say, but my doctors were kind and firm and reassuring and we're back on track again now with some drug therapy and a more positive attitude.

I've found this article extremely
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Loud Tie Day

Christine Lawton got involved in an excellent charitable event at St Marks recently. If you want to organise something to raise funds for the Red Lion Group, but have been lacking in ideas for what to do, this may give you food for thought...

On Friday 3rd November, I had the privilege of being able to help with Bowel Cancer Awareness Day, i.e. Loud Tie Day, at St Mark's Hospital.

I was just told to turn up, wearing a loud tie, and armed with as many other loud ties as I could gather.

I borrowed my brother's gold lamé tie (unknown to him) which scored quite a hit! When I arrived, I was greeted by Jo Sweeney, the stoma care nurse, and Eileen Murphy, the colo-rectal MacMillan nurse, who were helping to organise the day, and three other past patients, Jean Burke, Barry Kindred and Bob Azevedo-Gilbert, all being members of the Inside Out, the Stoma Support Group. They were all very kind and guided me, a complete novice in these matters, as to what to do.

A stall had been set up in the reception corridor, displaying the ties and information leaflets. The ties were given away to people in return for donations. Bob, I am sure he will not mind my saying, could charm the birds off the trees and very successfully persuaded many visiting the outpatients' clinic to go away happily sporting loud ties, even when they were outrageous clashes with what they were wearing! His success also may have been due to the very catchy Snoopy tie he was wearing, which had been donated by my vicar!

Jean and I left Bob and Barry at the stall and took a trolley around the hospital. We had a very good response. We were very touched by

the number of patients, who obviously had much on their minds, insisting on giving us donations. One elderly lady insisted that we open her locker for her and take a pound coin.

Staff and patients entered into the spirit of the occasion by wearing loud ties, including the bright rainbow cut-out ones that had been supplied by the promoters. A box of chocolates was later awarded to a patient in Frederick Salmon ward who had taken the trouble to put on a loud tie, even though he had only just had his operation.

We had much support and a really good laugh. The patients and staff were very generous indeed and

I was later delighted to hear that £330 had been raised.

The day was particularly enjoyable for me because for

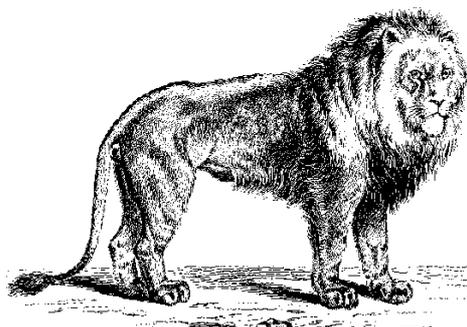
the first time I met a lady with whom I had been put in touch through the Red Lion Group and to whom I had often spoken to on the telephone. She has given me great support as I wait for my operation, due on 29th January. She was Sheila Keenan of Homerton, who very kindly took a few hours off work at Barts Hospital, in the afternoon, to come and meet me and help with the trolley.

Next year, I shall make sure I am there again. I have already begun collecting loud ties, as we ran out quite quickly this time. I am looking forward to it very much. We are hoping to recruit even more helpers next year, so we will perhaps be able to put stalls up in more than one place. If anyone wants to have fun while doing some very worthwhile work, watch this space!

Thanks go to the stoma care nurses and all the staff who helped to make the day go so smoothly.



Editorial



Well, now we are in the “real” new millennium, as defined by the purists (rather than those of us who liked the neat imagery of the change from 19.. to 20.. in the date), so the 21st century is finally, definitively and definitely here. Pretty much like the 20th so far, isn't it?

I hope you enjoy reading this issue of the newsletter. I certainly enjoy reading the articles which come to me for publication (although I would like to see more!). As you will see from this issue, we don't just print those which relate to pouch surgery or the stories of your medical experiences. Christine Lawton has written a piece about a hobby of hers, on which she will be able to spend more time during the period of recuperation after her surgery (now booked for January – best of luck, Chris!). Unfortunately, we are unable to get a decent black and white reproduction of the photo she sent which showed the banner she has painted for her Church – but I can assure you it was very impressive!

Julia Peters' article is a real eye-opener on how important it is to keep an open mind about the treatment that is necessary, especially given the fact that she is a registered homeopath herself. It certainly does not mean that complementary or alternative therapies are a no-no – simply that you should constantly reassess the effect they are having (which is also the case for any drug-based treatments), to ensure that they are not making matters worse rather than better. As someone who is very holistically-minded myself, I can appreciate how hard it was for Julia to face up to the

fact that drugs and surgery were unavoidable in her case.

An article which I imagine will touch a chord with many of you is Susan Walls' piece about the psychological effects of surgery for her. Normally Susan writes such upbeat stuff for us that I was very surprised a few months ago to end up having a much deeper conversation with her about how she really reacted to having her insides mucked about. I knew immediately that she would



not be the only one to feel this way and felt it would be helpful for her to put her thoughts into print, although I know it was not an easy topic to write about.

OK, I admit it, like the worst tabloid editor, I was actually thinking of the effect on our postbag. I have visions of lots of members rushing off to grab a pen and paper, to either agree heartily or disagree vehemently (and, yes, I know there's a split infinitive there, but what's good enough for Star Trek is good

enough for me...). Articles followed by letters means communication, and that is what this newsletter is all about.

Although many of you may not realise it, I am not a pouch owner myself (spouse of pouch, that's me), and so I can only contribute informative pieces – I need you the members to supply all of the experience which potential pouch owners are really interested in. Only you can tell them how it *feels*.

On a sadder note, I am sorry to report the deaths of Amanda Metcalf, who was formerly one of our reps, and of Leona Lederman. Leona was not a pouch owner herself but worked with great enthusiasm (and financial success!) at taking the merchandise trolley round St Marks. Both were great supporters of the Red Lion Group and our condolences and best wishes go out to their families.

One of the perks of being Newsletter Co-Editor for *Roar!* is the ability to pinch a bit of space for personal news. I am pleased to announce the arrival of the latest addition to our family, Thomas Louis Gaherty, on 4 December 2000 after a short labour. He is propped up beside me as I type this, but – I have to say – he hasn't proved much use on spelling corrections so far. On the other hand, sound effects (and the causes of them) are very much his forte...

Talking of which, why not join Bill Shepherd in writing to your MP and other ministers about toilets and their place in the proposed road access changes? Think on this: a hundred people talking are much louder than one person shouting.

You are what you eat

Dr Ed Westcott tells us more about the new trial at St Marks to identify whether enteral feeding improves the outcome of patients undergoing pouch surgery

As from now, we are recruiting patients into a trial at St Mark's Hospital. The study aims to find out if supplemental nutrition around the time of surgery decreases the complication rate of patients undergoing pouch surgery.

The aim of any surgical team is to improve the outcome of their patients both individually and as a group. No surgeon these days operates without using antibiotics at the time of surgery or taking precautions to prevent spillage of bowel contents onto the abdomen. These measures appear to have been exhausted with respect to post operative complications, as - even with the use of more powerful antibiotics and longer courses - septic complication rates remain constant. Almost 40% for pouch patients in some studies.

For many years it has been known that patients who are malnourished suffer more post operative complications. It is also widely recognised that drugs such as steroids decrease wound healing and the body's ability to fight infection.

You may think that malnourishment is a thing of the past in a country such as Britain. However, numerous studies have shown that approximately 30% of people admitted to hospital in this country are malnourished. This figure may well be higher for patients who have a chronic gastrointestinal illness such as ulcerative colitis. The even more staggering figure is that by the time patients are ready for discharge, 45% are undernourished.

Recently, there have been some encouraging developments in oral feeds, with the discovery that some nutrients which are part of normal

diets significantly alter the body's immune response in a beneficial manner. These are called Pharmaconutrients. Some of these nutrients prime the immune system ready for the assault on it caused by surgery, others direct the body to produce fewer inflammatory molecules which can be detrimental to recovery. Finally, there are a group of nutrients that your body needs for white blood cells to function properly.

In colorectal surgery we have always shied away from feeding patients soon after surgery, for two

of the study. Patients will be assigned to one of three groups.

Group 1: Will receive normal pre and post operative care

Group 2: Will receive 1 week of a normal feed similar to Fortisip before surgery and receive the same feed via a tube for 1 week following surgery to supplement their oral intake

Group 3: Will receive 1 week of a Pharmaconutrients feed before surgery and receive the same feed via a tube for 1 week following surgery to supplement their oral intake

We are optimistic that the trial will show that feeding pouch patients around the time of surgery improves their outcome by altering their bodies capacity to fight infection in a beneficial manner. Also of interest and hopefully of benefit is the stimulation of blood flow to the gut, which we anticipate will



reasons: firstly because of the risk of leaking in a newly joined bowel, and secondly because the gut stops working after abdominal operations.

Studies performed of late suggest that these worries are unfounded. Joins do not leak because of feeding, but may indeed heal better because of the supply of nutrients and the blood flow to the gut being stimulated by feeding. Following abdominal operations, various parts of the gut recover motility at different times. This means that if the stomach is bypassed by a tube, food can be delivered straight into the small bowel and absorbed soon after surgery.

We will be asking all patients who undergo pouch surgery at St Marks if they would like to be part

reduce the occurrence of strictures at the join between the pouch and the anus which cause difficulties in pouch evacuation.

This is a large trial and it will take approximately one and a half to two years to complete. It will involve nearly 100 patients, but at the end of it we may be a step closer to ensuring that pouch surgery is successful for more people.

If you are going to have pouch surgery at St Mark's you will be invited to join the study. You are under no obligation to take part in the study and refusal will not affect your treatment.

If you would like to receive more information please write to Dr Ed Westcott, Research Fellow, St Mark's Hospital (address as for Julia Williams, on back page).

Jumping for Joy

Well, she said she would do it, and she certainly did. Katrina Marshall tells us all about her very first parachute jump which raised £160 for the Red Lion Group towards pouch research. From all of us here at the Red Lion Group, many congratulations Katrina, and a big thank you.

Scary, exhilarating, breathtaking. All these words can spring easily to mind. I had always wanted and planned to celebrate my 40th birthday in style, and also with something different. Taking the plunge and booking a parachute jump would have to be the major feat to carry out and to overcome - or at least face - some fears of mine, like being afraid of heights. I didn't know whether I could jump out or not, or at the very least take the exam and pass it, as without the pass certificate you are not allowed to jump at all.

Saturday began with the formal booking, being weighed and the signing of numerous forms declaring that you don't hold the company responsible for any negligence on your part. We all completed the forms and began the mandatory classroom work, learning all about the equipment for skydiving and how to wear it properly. We had to learn how to use the equipment properly off by heart and, more importantly, the drills and proper countdowns to enable you to deploy the reserve chute safely, should the necessity arise (hopefully not). It wasn't dissimilar to being back at school some 23 years ago, going over theories and practical tests, working on them until you got it right first time, every time. The lessons were made more enjoyable by Sarah, our instructor. Having her teach us was a pleasure, and we learned so much, so quickly.

Our "team" consisted of four members of the Firs Fitness Club, of which at the time of the jump I was a member of staff. The remainder were a group of people from other professions. It was also nice to meet and get to know these new friends of ours on this daring and truly exciting adventure, over the two days it takes to prepare for the jump.

Each of us gave the others maximum encouragement, and that made the days and training even more pleasurable.

The drills that we had to learn included exiting the aeroplanes safely and finding that you are in the great



rush of air, and a fair way up from the beautiful, safe, green grass. Also, we had to know how to open the chute ourselves if necessary, even with the heart going like the clappers. Hopefully that would not happen, as we were preparing for a "static" jump, where the chute will automatically open once you jump from the plane using a "static line" (one end connected to your chute, the other to the plane). We also needed to learn how to recognise the "drop zone" area, where we were supposed to steer the chute to make the best possible safe and comfortable landing.

I cannot lie, all manner of evil thoughts and "what ifs" kept creeping into my mind. What if the chute didn't open properly or not at all, what would I do if I'm blown off course, and the thought of landing in a field full of sheep and soft sheep droppings ... oh, lovely!!! Trying hard to suppress all these fears and just trying to make it a great day was a feat in itself, but surely all these fears would be laid to rest soon enough.

All this worry and adrenaline pumping through my veins was for a very good cause, having had surgery then many years of treatment for a major bowel disorder. Making this jump was my way to help and raise funds to assist in ongoing research, and this certainly made going through with this more bearable and worthwhile.

Then came the day of the jump. Having passed the written exam, I was ready to face the day. Having not eaten the day before, the butterflies were really going to town on my stomach and nerves. We were asked to register and make our way to the changing room. Getting into the overalls or "jumpsuits", most of us tried to put on a brave face, and there was certainly a lot of nervous laughter amongst the group. Maybe we were just trying to get it all over and done with. Having got all the gear on properly - my God, what a weight! It nearly toppled me over, down here on the ground. It worried me a tad, thinking about how quickly you would descend once you were in the big blue sky, with all this on.

Making our way to the plane seemed to take ages, waiting in line to board. As for finding out that I was to be the last one on, but (even worse) the first one out ... help!!!! Somebody had nominated me as team leader - thanks a bunch, who-

ever you were.

It was frightening at the time but, looking back, I'm glad I was the first to jump. Maybe if I had had the chance to think and watch the others go I might have lost my nerve and refused to jump from a perfectly serviceable aeroplane, knowing it was going to make a perfect landing some time later anyway. Getting "hooked" onto the plane through the static line made me realise that there was no going back, and it was time to put all that training into practice.

Here goes! I move forward to take up the fall out position. My God, that looks way, way down ... and JUMP!!!

With all my might, I launched myself forward, quickly looking up so that the camera could catch the look of absolute horror on my face. What a picture that would make.

One thousand, two thousand, three, four, look up to check the canopy - thank you, God!!! It opened, and I heaved an almighty sigh of relief. To tell the truth, a few little tears came into my eyes. I'd never been so nervous in my life.

It's surprising what a calm, peaceful descent you make, once you get over the worst of your fears. I steered the chute to within thirty five feet of the marker point. Not bad, if I say so myself, and I made what the ground marshal said was a brilliant landing, rolling sideways and right into a deposit left by those damned sheep, as did everyone else. I now think they may have been taught to do their ablutions just where the instructors wanted them to. Thankfully they had dried up a little.

Collecting my thoughts, my nerves and the chute, I made my way to the boundary to await my fellow parachutists. We all had a good loud cheer once everyone was safely down to earth. A nice touch was the big round of applause from all the instructors and our own family members who came to watch our momentous jump - that made us all feel ten feet tall. The thrill and excitement certainly did it for me, and I would gladly do it all over again, given the chance.

Five Star Thesis

Chris Browne provides a review of Monica Melling's thesis on the pre and post operative experiences of pouch owners.

First there were *The Confessions of a Window-Cleaner*, then *The Confessions of a Safe-Cracker*, and finally, *The Confessions of a Chimneysweep*. Some of you may remember those wacky comedies of the 1970s starring Robin Askwith. Today, however, we have the *Confessions of a Pouch-Owner*. This version, however, is a serious study, not a zany farce, and tells the story of ten pouch-holders and their experiences before and after surgery.

"Living with Ulcerative Colitis: Chronic Illness, Quality of Life and Health Promotion" was written by former Red Lion Group secretary Monica Melling for her masters degree at King's College, London. Though it was an academic work, Monica shows a refreshingly light touch, combining the skills of historian and journalist. It is perhaps not surprising that her thesis was given a distinction and the second highest marks of her year.

You may well recognise yourself among the ten case histories - I certainly did - though, in the interests of confidentiality, Monica has changed the names. Ages and occupations vary, and include a soldier, a graphic artist, an engineer, a nurse and the views of 13 year old "Louise" among others. As we all know, early experiences of uc, polyposis and Crohn's have fleeting moments of absurdity, accident and anecdote, in the same way as the *Confessions* films, but it is a galling phase that most of us choose to forget.

What makes Monica's work so vivid is the way she has tape-recorded her subjects, editing, cutting and deploying the skills of the reporter to extract such quotes as: "Colitis is probably the worst social disease in the world", or "Steroids make me look like a cotton bud ... a big head on a thin body" (see cartoon!). As a former uc sufferer herself, she is able to delve into the inner recesses of illness and tackle

its effects on Relationships, Work, Social Life, Pregnancy and the Concept of Self.

Monica, who lives in south-east London and works for a London health promotions company, was aided by a Red Lion Group grant to help with the printing and publication costs for her thesis. She also had to interrupt her thesis for ileo-anal surgery, but interestingly her experience adds a certain sharpness and deftness of touch to her writing.

A moving picture emerges of ten individuals using humour in the face of adversity at home, at work and when meeting friends, colleagues and loved ones at official and social events. All of them display long periods of courage and determination, and only rare moments of pessimism. Many found hard work and/or an extrovert nature helped them through, while the adage "physician heal thyself" gave others an insight into their illnesses, helping them to grasp their problems, seek advice and then act on it.

Monica highlights the value of support groups like ours, healthcare professionals who monitor patients' progress and well-being, and the need for greater information and education about colon illnesses and surgery - especially before operations. As she concludes: "If surgery is the ultimate option, let it be a positive choice rather than a blind journey."

In my dual role as guinea pig and newspaper reporter, I award Monica ***** and a Highly Recommended award for her poignant and painstaking writing and research. Congratulations.



Letters



**Roar! Letters Page
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Dear Newsletter Editor

I had my J pouch operation at Derriford hospital, Plymouth in March 1998 at the age of 33 years after a history of ulcerative colitis. Two years hence I am pleased to say that I am very happily married and expecting my first baby in February 2001.

So far I have had a good pregnancy with little medical intervention but since the 6th month I have noticed changes for the worse in the behaviour of my pouch. Whereas prior to pregnancy I seldom got up to empty my pouch at night, I now need to empty it 6 or 7 times. The output is mostly liquid but it seems to burn more and even the Vasogen cream doesn't keep my tail end from severe itching and soreness. Mostly the soreness comes from inside my back passage. All in all I don't seem to be able to hold any degree of liquid in my pouch or to expel it when I want to, but I am hopeful that the pouch will settle once the baby is born. I do not cherish the

thought that I will be pampering the baby's bottom as well as pampering my own but it keeps me in good humour.

The whole birth experience is shrouded in mystery and ignorance. The midwives are keen to promote Natural birth for all and advise me to keep an open mind with the reassurance that my uterus will behave normally even if my bowels haven't! The obstetrician who might be performing a caesarean section is vague as to the mode of delivery and certainly at all my antenatal visits thus far I have felt a bit of a freak. Pregnant pouchies are obviously very unique and rare people given the lack of knowledge that exists.

At the end of the day I am sure that I will act upon the recommendation of my surgeon who advises an elective caesarean and obviously knows the risks involved to me with a normal birth. However I do wish that someone would tell me what exactly these risks to the pouch or sphincter muscles comprise of and the likelihood of them occurring, particularly as I read in one of your issues that in the USA pregnant pouchies are encouraged to give birth the way nature intended.

If there is anyone out there who has experience of either caesarean birth with a pouch or natural birth with a pouch I would greatly value sharing your experiences and in particular how you coped postnatally.

Any replies can be directed to my email address
Amanda.white@tesco.net.

Yours faithfully
Amanda White

Ed note: Since writing to Roar!, Amanda tells me her current pouch problems have been diagnosed as cuffitis, and she is keen to hear from anyone else who has experience of this condition.

Dear Newsletter Editor

I read the latest issue (18) of *Roar!* magazine with interest.

I was rather concerned about the negative comments concerning the pouch. I have now had my pouch

for ten years (in April 2001). When I compare my life prior to the operation and my life after, I am very pleased I had the operation and would make the same decision again. I was a sick, frail, very ill person in 1990 who could not even walk to the end of the road because I needed the toilet all the time. Ten years later, I'm now a fairly fit person who can enjoy long walks, eat pretty well what I like and generally enjoy my life to the full. In short, the pouch gave me a new lease of life at the age of 35 and I am extremely grateful for the carefree life I now have.

I'm not trying to say that the procedure is perfect, as problems can and do occur. I have, for instance, had six episodes of obstructions that have required hospitalisation, caused by adhesions. Taken on balance, I consider the pouch operation worth having.

I was interested in the bit on the front page about possible failure of the pouch "20 years down the line". I have never considered this before, but all I can say is that I hope mine lasts as long as I need it. I have had nearly ten years without a bag that I would not have had, and if it only lasts another ten years I'm still very grateful for what I *have* had.

Yours sincerely
Judith C Harris

Dear Newsletter Editor

I read *Roar!* newsletter and find it very useful and informative. Keep up the good work. In issue 18, I was very interested to read a letter by Joanna Reed concerning the pouch and arthritis. Thanks to you, I am now in contact with Joanna.

I was interested in her letter because I have also developed arthritis, but as I had UC for over 25 years, I cannot say that I didn't occasionally get painful joints and other complications whilst having a relapse.

I also have a family history of IBD and arthritis. As well as my own UC, 2 of my 4 children have either UC or Crohn's. I thought ours

was the only family with 2 siblings with bowel disease and have only read about families where it has "passed" from one parent to one sibling. I would like if possible to contact any other families with a history of IBD and siblings with IBD so that we can exchange experience. Also, anyone who has the pouch and arthritis.

I can be contacted by phone on 01603 712227, fax on 01603 714897, e-mail using info@exploration-electronics.co.uk and post at "Robin Hill", 8 Strumpshaw Road, Brundall, Norwich, Norfolk, NR13 5PA.

Yours sincerely
Mrs S E Allen

Financial News

Morag Gaherty reports.

First of all, I should like to congratulate Katrina Marshall for raising £160 in sponsorship money from her parachute jump in the summer. This money is to be allocated towards bowel surgery research, as she requested. As the Red Lion Group itself does not (as yet, anyway) have the funds to get involved with research matters, we will make an equivalent donation to the Marksman Appeal, who do, so that the money gets into the appropriate hands. This donation will be voted on by the members at the next AGM.

Secondly, last quarter's newsletter contained a Gift Aid form, together with an explanation of how completing this form enables the Red Lion Group to benefit by £2.80 for every £10 we receive in either donations or subscriptions from our members, at no extra cost to the payer. Many of you have already completed and returned the form (which applies to all payments in this and future tax years, even if they have already been made), for which I thank you.

If you are a taxpayer and have not yet sent your Gift Aid form to John White, let me urge you once again to do so - it costs you nothing except the price of a stamp, but the Red Lion Group can benefit significantly. This is not just for those who make donations above and beyond

the value of their subscription, but for all of those who are Red Lion Group members.

Last year, we sent out raffle tickets for the Alexandra Rose Day Autumn raffle with issue 17 of the newsletter. Many thanks to all those who bought them. Remember, for every £1 of tickets sold, the Red Lion Group receives 80p, so we as a charity benefit, whatever happens to the prizes. And the prizes available are far more generous than we could afford to offer, should anyone be lucky enough to win one.

The Red Lion Group raised over £100 from ticket sales for the Autumn raffle, despite the fact that the newsletter went out quite close to the deadline for returning the stubs and the money. Because of how our quarters fall, we either have to send them out very early or very late. For the Spring raffle (to be drawn in May), we are doing the opposite and sending the tickets out with this issue rather than with the next.

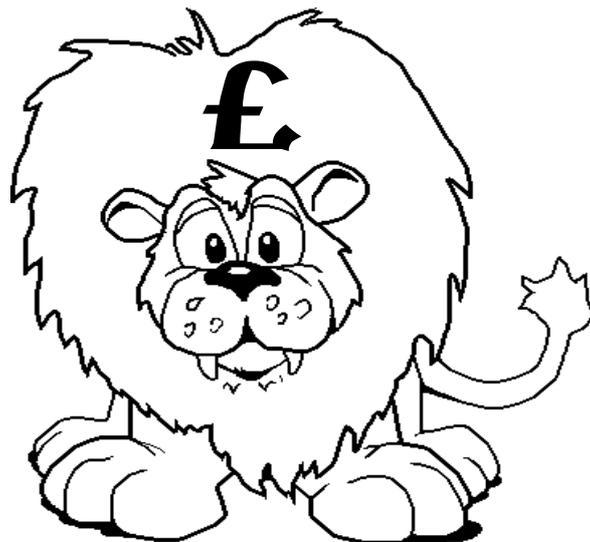
The raffles are held twice a year.

Tickets will come out with alternate editions of the newsletter. Of course, you do not have to buy them every time, but the more you buy the more we benefit. One book is sent per member, but more are available from me on request. Perhaps you have friends or relatives who might be prepared to buy a ticket or two.

This time, let me give you proper information about what to do, as I inadvertently forgot to do this in issue 17! If you or your friends would like to buy any raffle tickets, please complete the stub with your name and full telephone number (including area code), and return this with your payment to our Treasurer, John White (address on back page) by 1 May 2001. Please make your cheque payable to Red Lion Group.

Let me thank you again for supporting the Red Lion Group in this way, and let me also wish you the best of luck for the draw! If anyone does win a prize, please let me know, so I can put the news in the next issue of the newsletter.

Please support the Red Lion Group



All donations, however small, towards expanding the work of the group will be gratefully received. If you would like to send a donation please make your cheque payable to The Red Lion Group. And send it to: **The Red Lion Group Treasurer, Mr John White, 44 France Hill Drive, Camberley, Surrey GU15 3QE**

My Story...by Wendy Hinde

I am always interested in hearing other people's experiences who have had a pouch operation. This is my story.

I started suffering from UC whilst pregnant with my second daughter. At my routine checkups I kept saying that I was losing a lot of blood from my back passage. They said it would just be piles, which I accepted, and thought the feelings of sickness, upset stomach, pains etc were related to my pregnancy rather than to anything else.

After one such routine checkup, I was recalled by phone that same afternoon and requested to come for a stay, as I was very anaemic. I was given a blood transfusion, seemed to be sort of OK and was sent home.

I was OK for the rest of my pregnancy and delivered a beautiful baby girl, Michelle, weighing 8lbs 2oz at 2 minutes to midnight on the 23rd of December.

I went home on Christmas Eve a very happy new mum, as I had wanted another little girl, a sister for Jacqueline who was 2 at the time.

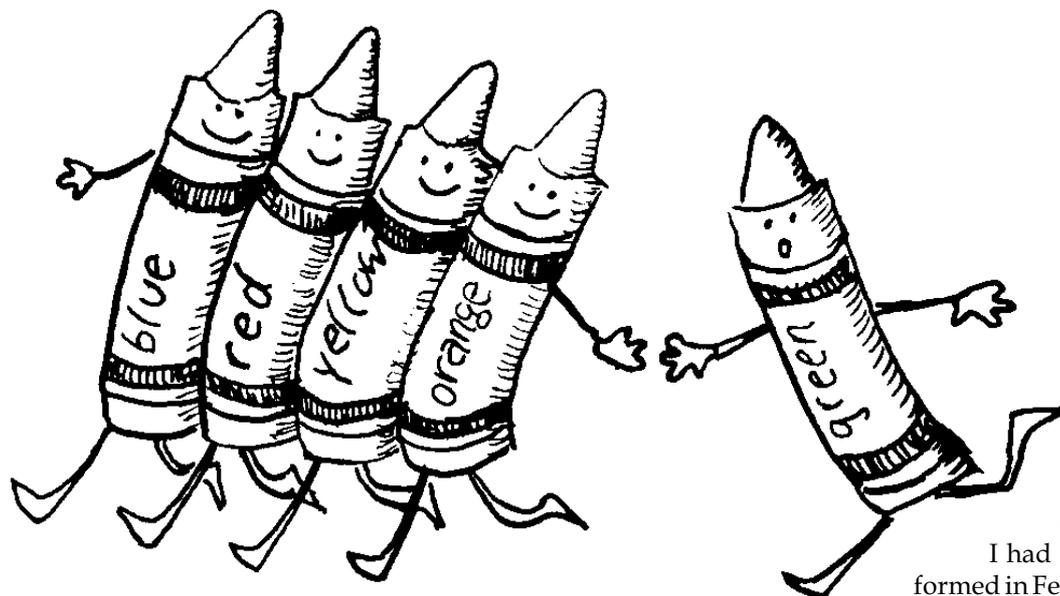
I seemed to be fine for a month or two, but then started to have the runs again, losing blood and passing mucus. I was losing weight fast and feeling very unwell.

After visiting my wonderful GP, he referred me to hospital and - to cut a long story short - I was diagnosed with UC. This could not be controlled and I was in hospital more than out, and given umpteen blood transfusions, which seemed (to me) to go straight through me. My consultant used to let me home at weekends - "out for good behaviour", so

it seemed.

Luckily, my parents-in-law had moved nearby, and they helped my husband cope with 2 young children. We know we could not have coped without their help. They were tremendous in their support and love for us all.

I was sick of tablets and visits to the loo, so I kept a chart in hospital. When it got to over 30 visits in 24 hours I wondered how this could go on. At last, I was gaining weight (because of the medication), but I hated looking "moon faced". Peo-



ple would say "you look well" and I would just smile and say "yes, I am, thanks".

Then my consultant retired and a new one came along. Mr Robin Knox was, and is, my saviour. He asked if I'd heard of this pouch operation and gave me details. He left me alone to think things over and talk to my husband. It seemed great - *no way* did I want an ileostomy at my age. The very thought of it made me ill (more ill!).

After a few weeks and more blood transfusions and drugs, we decided that, yes, I would have this op. I was the first in Harrogate to have this procedure performed and I was scared, to say the least. The nurses didn't know anything about

it either, so we learned together. One nurse did a case study on me, and we became firm friends.

It was tough going, no doubt about it. I absolutely hated the ileostomy, and it hated me. I leaked, and it wouldn't stick to me as I was allergic to every adhesive used. I had a solid blood-red ring round my stoma.

I cried a lot and hated myself. I couldn't bear what had happened to my body image. I have always taken pride in my appearance. I wear makeup every day and do my

hair and nails. My consultant says he always could tell when I was feeling really poorly, as I didn't make myself up when I was really down!

I had my J pouch formed in February 1988 at the age of 30. Since my

operation, I have never looked back. Yes, I had a few hiccups: a small fistula into the front passage, soreness and stomach pains. But this is nothing compared to the thought of an ileostomy.

I am 42 now and work as a teaching assistant in a special school in Knaresborough, as I have done for 12 years. It was the first job I got after the operation and I can honestly say I've never had a day off because of my pouch, except whilst in hospital initially for checkups. I don't think I've ever had pouchitis.

Maybe I am the lucky one. I certainly feel lucky to have met Mr Knox, my surgeon in shining armour, and to have a loving supporting husband and family.

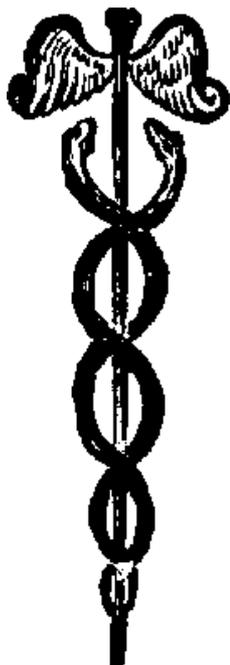
Medicalert Bracelet

We mentioned this bracelet in a very early issue of *Roar!*, but the time has come to mention it again, for the benefit of newer members.

If you have any kind of pre-existing condition or treatment requirement which may need to be known in the event of an emergency, it makes sense to have some form of recognised information about your person. For instance, a person with an ileo-anal pouch should only have a paediatric endoscope used on them, so that the pouch area is not damaged by over-large instruments. Or it may be advisable for emergency personnel to be aware that you take steroids for your condition.

There may be many other reasons unrelated to UC or your pouch why a Medicalert bracelet could help you. Perhaps you are allergic to certain medications or maybe you have some form of implant (a pacemaker, for example) which is not obvious from the outside.

In any event, the safest way to ensure that this key information is passed on, even in the event of you being unconscious, is to wear a Medicalert bracelet or pendant. This



bears the internationally recognised medical symbol on the front, and your medical condition, personal identification number and Medic Alert's 24 hour emergency number on the back. When needed, health professionals can get further vital medical information about you by a telephone call from anywhere in the world.

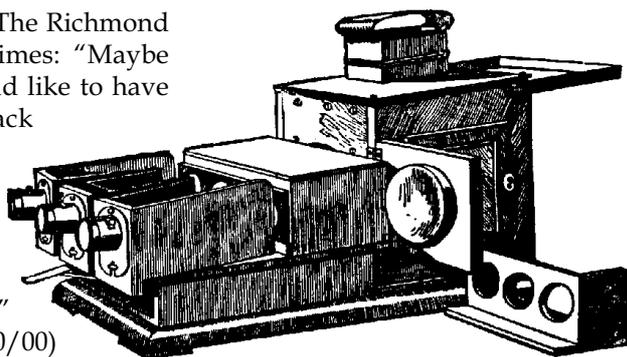
So how much does it cost? There is an annual fee of £10 for keeping your records on computer and up to date, and then there is the cost of the bracelet or neck pendant itself. This starts at £19.95 for a stainless steel version, but for those who want the luxury of solid 9ct gold, be prepared to pay up to £180!

For more details and an order form, contact the Medic Alert Foundation on 020 7833 3034. Medic Alert is a non-profit making registered charity (number 233705) and all of the revenue is used to benefit the members.

Shame on the council!

We're not saying the Daily Telegraph is bowel-fixated, but here's yet another snippet contributed by the ever-vigilant Sandy Hyams:

From a letter in The Richmond and Twickenham Times: "Maybe other residents would like to have pictures of their back passages published to 'name and shame' Richmond Upon Thames council into having them cleared out." (Daily Telegraph 3/10/00)



Vitamin B12 update

In the last issue of *Roar!* (18), the subject of pouch deterioration over time was raised, as was the question of Vitamin B12 testing. Since then, we have received a few queries from members requesting clarification of these points.

Julia Williams, pouch support nurse at St Marks, has the following information to offer:

"The pouch does not deteriorate over time, but in some cases the absorption rate does. This therefore necessitates annual blood tests, particularly for Vitamin B12. This should commence from five years post pouch formation and can be undertaken via the GP."



Red Lion Group Christmas Cards

Many thanks to those of you who bought these and our apologies at how long they took to get to you. Unfortunately, we had reckoned without Parcel Force losing the parcel on its way to St Marks for nearly 3 weeks! For anyone considering using Parcel Force in future, please note that their "standard service" gives no guarantees about delivery times, they will not even look into missing items until 10 working days after posting, and they cannot track them on their system even if you have the "trackback" barcode (which we had). In fact, I am having some difficulty in understanding how this qualifies as a "service" at all.....!

Wherefore Art Thou?

I am hoping during recuperation from my forthcoming operation at the end of January to find more time to indulge in my favourite activity – art. I have found this a relaxing and enjoyable pastime ever since I was about five years old, though I don't think I've improved much since then!

I would certainly recommend it for whittling away the boring hours when you can't do much after surgery, or for that matter, when you become tired and frustrated and just want to express yourself and get something out of your system. It can be totally engrossing.

I am keenly awaiting the Spring so that I can begin my flower painting. I travel with my job so sometimes flower paintings take a couple of years because, halfway through a painting, I am sent away, the flower dies and I have to wait until the next year before I can complete it from life, which I prefer. The result of this is many unfinished paintings and much patience!

Once read about a patient who, while in hospital, began sketching portraits of his fellow patients. They were very much admired and when

he left hospital he became quite a successful portrait painter and received many commissions. I certainly don't think I will be following in *his* footsteps; he was obviously very talented.

One of my projects has been to paint banners to liven up our large but modern church, St Cuthbert's in North Wembley. It has many plain



walls, crying out for some decoration. As a result of a plea from our vicar, various people have made banners, some sewn and some painted. Mine are painted in acrylics. The last one I did was on the theme All Things Bright and Beautiful and took me quite a long time. Happily, acrylics have the advan-

tage over watercolours because you can correct the mistakes fairly easily – it's just as well that banner has never been X-rayed! I am hoping to do a few more.

Therefore, if you are feeling at a loose end, fed up, nothing to do but sit around waiting for things to heal and feel better, why not have a go? You don't need to be able to draw a

straight line and you will be surprised what you find you can do – if you can't, what does it matter? It's the process of doing it rather than the finished product which is so therapeutic. There are also many good teaching videos out now, with some very good hints, which I would recommend, and there are unlimited media to try.

My aim is to become more proficient, study some art videos, books and magazines and maybe,

when I am better, try an exhibition somewhere in aid of the Red Lion Group – this might very well be over-ambitious but it is a goal to aim at!

If you want any help or advice on how to begin, do contact me and I will do my best to help. Good luck with your efforts.

Putting Pressure on MPs

Bill Shepherd wrote to his MP about the effect of private transport disincentives (such as those proposed by Ken Livingstone) would have for incontinence sufferers, and sent the same letter to 5 ministers and their shadows. It is this kind of pressure which gains awareness and - more importantly - gets results. A version of his letter is reproduced below for you to use similarly, if you could spare the time to help.

You can contact your MP or any other named minister by writing to them at: House of Commons, London, SW1A 0AA.

Bill later received a reply from the Department of the Environment, Transport and the Regions (DETR), to whom a copy of his letter had been passed. As the lady who sent this is one of the officials responsible for this policy area, it would be well worth writing to her directly. Her details are:

Mrs S D Hemmings
Charging and Local Transport Division
 DETR
 Zone 3/07
 Great Minster House
 76 Marsham Street
 London
 SW1P 4DR

Another person who would be well worth contacting is the Minister for Transport. His details are:

The Rt Hon Lord MacDonald of Tradeston CBE
 Minister for Transport
 DETR

Eland House
Bressenden Place
 London SW1E 5DU
 E-mail:

angus_macdonald@detr.gsi.gov.uk

So what are you waiting for? Get writing, and make pouch owners a force to be reckoned with!!

Sample letter for MPs and other ministers

"Please can you help me and many thousands like me. I suffer from a disability that is not talked about in polite company. That disability (which is recognised as such by RADAR) is incontinence.

I suffered from ulcerative colitis for many years, until it got so bad that I had to have an operation to remove my bowels. I was then fitted

with a colostomy bag.

Let me tell you a bit about a colostomy bag. You have very little control over how quickly the bag fills, unless you don't eat for many hours. It can get knocked in error, it can fall off if it gets too full or if the wearer (like I do) produces too much acid. The thought of being trapped underground in a tube for two hours, such as happened some weeks ago, fills me with panic. The idea of being jostled on a busy train is equally unattractive.

I have been lucky to become a patient of Professor Nicholls at St Marks hospital, and so I now have an ileo-anal pouch instead of a colostomy bag. Effectively, this surgery creates a "bag" inside my body, so it cannot get knocked off. However, it does not return full bowel control, and so rapid access to toilets is still a necessity. I now usually get 15-20 minutes' warning of the need to find a toilet, and I hope that this will improve over time with "pouch training". Not everyone with a pouch is so lucky.

You can find out more details about pouch surgery and its implications by contacting the Red Lion Group, a registered charity which provides support to pouch owners, at the following address: c/o Stoma Care Department, St Mark's Hospital, Northwick Park, Watford Road, Harrow, HA1 3UJ.

My main worry is public transport, because toilet facilities are simply not adequate for people like myself who suffer from incontinence. I am therefore reliant on my car, not just to get to a toilet whenever I need to, but also because everywhere I go I have to carry a change of clothing and relevant toiletries. Current discussions about congestion charges and other access restrictions are of great con-

cern to me, as they will make my life even more difficult.

Life can be very embarrassing for me and uncomfortable for people with me. I have been treated with disgust by people who don't know or understand my problem. So you can see why I need the travel privacy of my car, and the feeling of safety provided by my first aid kit and the book supplied by RADAR which lists every disabled toilet in the country.

So this is my request: please put forward my case to the necessary officials, so that people with incontinence will be recognised as disabled for the purposes of access to restricted areas which may arise because of congestion planning. Also, disabled toilets are not always accessible from existing parking areas, and some understanding from local authorities (and parking officials!) would help in this regard. I can walk very well, but do not always have time to find a meter, when a toilet is my urgent priority.

I appreciate that it is not practical or desirable to issue orange disabled badges to everyone who is incontinent, when our problem is restricted to the need for rapid access to toilets. Perhaps some kind of official card, to put on the dashboard, which could certify me as eligible to bypass parking restrictions for a limited period of time (say ½ hour), on which I can show the time of arrival (like the French "blue disc" in restricted parking areas) might be a solution? This might also allow exemption from road access charges or similar.

The alternative is that there will be many places we cannot go, restricting family activities for the many who suffer like me.

I look forward to your reply.
 Yours sincerely"

My Story... My Mistakes!

Julia Peters, registered homeopath and soon-to-be pouch owner, tells us her story. If you would like to contact her, her details can be found in the advertising supplement with this issue.

I joined the Red Lion Group in October 2000, and noted from the backdated copies you kindly sent a recent article on homeopathy. This, combined with enjoying hearing about the experiences of other readers, gave me the impetus to write down my own story.

My career as a homeopath started over thirteen years ago, and during that time I have seen a number of patients with ulcerative colitis. Most have come soon after diagnosis, and have been quite easy to treat. Not always though; one man came with a long history of steroids, that were no longer effective, and in spite of my best efforts I was unable to help him. I remember being particularly disturbed by this case, and perhaps it was some kind of premonition, since a year or so later I myself started getting ill.

Things started to go wrong in the spring of 1998. Initially it was problems with my teeth and gums...massive mouth ulcers, recurrent abscesses, and I generally felt tired, listless and unwell. In May I developed diarrhoea and a few weeks later I was passing blood. At the time my relationship was under a lot of stress and, coming from a holistic background, I put the symptoms I was getting down to this. I treated myself with homeopathy, cranial osteopathy and aloe vera juice. At one stage I was hardly passing any proper stools, simply blood and mucus with constant urging, but still I did not visit a doctor. I guess I saw them as 'the enemy'.

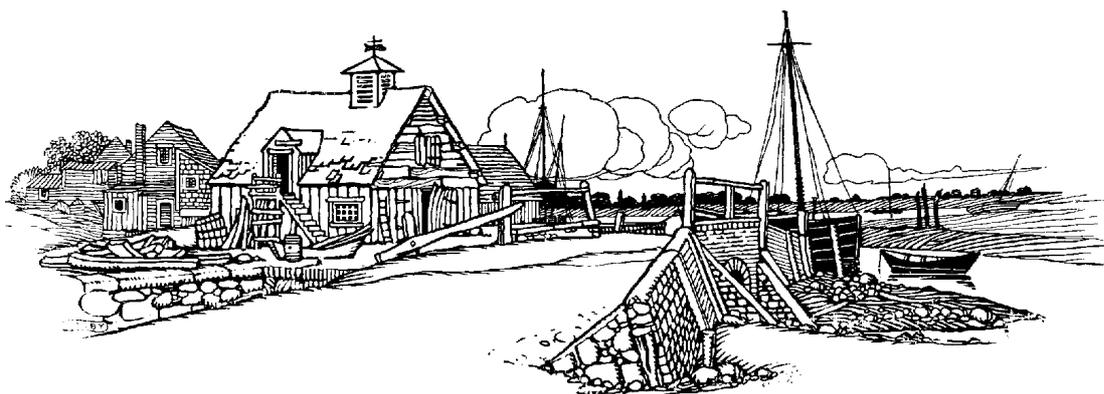
Fortunately (and I did not ap-

preciate quite how fortunately at the time!) my symptoms gradually abated, and by the end of July I was considerably better. I did, however, continue to get mouth problems and awful toothaches and my periods started to go haywire, sometimes four or five months apart, but I put this down to the menopause approaching.

That winter was not too bad, though I was a long way from my previously healthy self. Then in May '99 the diarrhoea began to recur. I tried the various approaches I had

weeks I was delighted to be symptom free and feeling much better.

In December the stress I was under escalated (parents this time!) and the situation deteriorated quite rapidly. I was once more horribly constipated, along with the blood and mucus, and on the advice of a friend, brewed myself a powerful herbal concoction supposedly to relieve this. Not surprisingly this proved to be a big mistake, and I began to get a great deal of pain, and felt generally worse each day. The hospital gave me steroid enemas,



used before, including acupuncture this time, but to no avail. The day after the August eclipse I felt my health take a further plunge, with a recurrence of the blood, mucus and constant urging. Still I did not see a doctor; just got more rest, went to counselling with my partner, and hoped it would go away. It didn't. In October I finally saw my GP and a few weeks later was diagnosed by Dr Vicarey, my consultant at the Whittington Hospital, North London, as having ulcerative colitis. By this time of course I had a pretty good idea myself, so it was more of a confirmation really. Dr Vicarey was extremely supportive and understanding, and I was relieved that I did not need to take steroids. He prescribed Asacol, and for a few

which did not help. Still I refused to really appreciate how serious things were. I continued working, as being self employed meant no work no money, and convinced myself that a proper rest over the Christmas holiday would put matters right.

Christmas Eve I felt absolutely dreadful, but my partner was working and I struggled out to do the shopping. I got back, left the bags in the hall, fell into bed and remained there for the next six months! I guess everybody reading this knows how awful the nightmare of acute colitis is. Forceful stools, passed maybe thirty times a day, rapidly resulted in terrible painful piles. After a lifetime of excellent health I could not really believe this was happening to me. Every other trauma I had ever

been through faded into total insignificance next to this. I decided that the drugs I had taken had simply aggravated things, and convinced myself that with bed rest my body would eventually heal itself. So strong was my holistic vision, I guess it was my 'religion', that I felt if I had the will and courage to stay the course I would get better and it would be permanent. I told myself if I resorted to steroids it would just keep recurring, and I would never be a 'normal' healthy person again.

Whatever my will said, my physical body was rapidly disintegrating. By the time I went to stay with my parents towards the end of January, I had lost over two stone, and I was not overweight to start with. My parents were horrified and, understandably, insisted on calling a doctor. Various blood tests were taken, which painted a very gloomy picture, and all four village GP's attempted to persuade me to go into hospital. They also told me I would almost certainly need a colostomy, and I said, sincerely, that I would prefer to die. I did ask about the possibility of a temporary bag, but was told this was not possible, since the whole colon would need to be removed.

After a couple of weeks my parents could no longer cope with the stress and I came back to London. My teenage son, studying for his 'A' levels, did a brilliant job of looking after me, helped by my partner (unfortunately working long hours) and a number of wonderful friends. I was endeavouring to avoid wheat and milk, since I felt these aggravated my condition. This did make finding easy things to eat more difficult, and I was grateful to friends for bringing home cooked food and trying to fatten me up.

By early March I felt I was improving. I kept an appointment I had with Dr Vicarey, who had me admitted right away for a blood transfusion. I could only walk a few yards and was completely exhausted. I refused further treatment.

With my haemoglobin levels restored I felt markedly better, and was convinced my journey back to health was underway. I was still

passing stools a dozen times a day, but at least they were more formed and less bloody. The piles were the worst aspect throughout this period, with each stool feeling like some agonising medieval torture.

Later in March I developed a raised, red itchy rash that covered most of my body; probably due to lack of proper nutrition/absorption. Consequently my sleep was even more disturbed. Lying in bed was a torment since I was so thin, I had been bedridden for so long, and now my skin was really sore. There was no way I could get proper rest and, not surprisingly, my symptoms relapsed. In early April I felt I was back to square one again.

At this point I *finally* accepted that I was not getting better, and I went into hospital. The staff there on Rickett Ward were terrific. I was in an incredibly poor state of health, largely inflicted by my own obstinate stance, but nobody even hinted at judging me or ridiculed my attempts to do things in my own way. I was given lots more blood and intravenous steroids, but did not respond sufficiently. Ten days after going into hospital I surrendered to losing my colon.

At first all went well, though progress was slow, doubtless due to the abuse my body had already suffered. After a week, however, I found myself suddenly in tremendous pain and needing increased doses of morphine. I became less and less able to eat and food was getting obstructed. My weakened immune responses had been further suppressed by the steroids and test results were confusing. The surgeons were naturally trying to avoid another operation, and were hoping that heavy doses of antibiotics would resolve matters. I was being tube fed by this time, but since my heart was racing and my metabolism fast the weight continued to drop off. Eventually, three weeks after the first operation, my wonderful surgeon, Mr Lock, opened me up again and removed adhesions and a large abscess. After this I did progress, though eating was a nightmare for some time since I was out of practice and my gut had been

so abused. The last hurdle was getting off the morphine; a horrible few days, as after five weeks constant usage my body and psyche were quite addicted.

I left hospital at the end of May, having lost in total over three stone. I was very frail and weak, but fortunately my mother came to look after me and, with tempting home cooked food, I gradually began to manage better and gained some energy. After a week I was able to cope with preparing food for myself and since then have gone from strength to strength.

The piles have become a permanent feature and are due to be operated on in December; followed in due course by the pouch surgery.

I am hugely grateful to the NHS, and glad to be rid of those old deep rooted prejudices I had previously. I feel my work as both counsellor and homeopath has benefited enormously from this experience; I have realised that before I had some pretty arrogant views and judgements about the causes and nature of illness and suffering. I am grateful to have come through, and have found a beautiful silver lining at the centre of that very dark cloud.

I only hope other readers feel similar after the tough physical journey life has put us all through.



Invasion of the steroid heads

Regional Reps

Here is our current list of regional reps with home telephone numbers – please feel free to contact your local rep and get acquainted.

If you would like to be a Red Lion Group rep, please contact Morag Gaherty (phone number on back page).



AVON

David Mair Bristol 0117 922 1906

BEDFORDSHIRE

Wendy Gunn Luton 01582 423714

BERKSHIRE

Liz Davies Langley 01753 586593

CAMBRIDGESHIRE

Joyce Shotton Peterborough 01733 706071

CLEVELAND & NORTH YORKSHIRE

Christine Jackson Saltburn 01947 840836

CUMBRIA

Jonathan Caton Kendal 01539 731985

DERBYSHIRE

John Roberts Derby 01332 361234

DEVON

Gill Tomlin Kingsbridge 01548 810028

DYFED

Briony Jones Haverfordwest 01437 765359

Bruce Dibben Haverfordwest 01437 731436

EAST SUSSEX

Lisa Critchley Brighton 01273 699286

ESSEX

Peter Zammit Benfleet 01268 752808

Clare Shanahan Ilford 01708 444359

GWENT

Robert Challenger Cwmbran 01633 866820

HAMPSHIRE

Phil Smith Portsmouth 01705 426541

Les Willoughby Winchester 01962 620012

HERTFORDSHIRE

Carol George Stevenage 01438 365707

KENT

David Irving-James Folkestone 01303 894614

Phil Elliment Barnehurst 01322 558467

LANCASHIRE

Joan Whiteley Clitheroe 01200 422093

MERSEYSIDE

Blanche Farley Liverpool 0151 286 2020

NORFOLK

Sandy Hyams King's Lynn 01485 542380

Sylvia Mist Norwich 01692 580095

NORTH LONDON

Susan Burrows 020 8882 5318

NORTHAMPTONSHIRE

Cynthia Gunthorpe Kettering 01536 482529

David Smith Northampton 01604 450305

SOMERSET

Clive Brown Chard 01460 234439

SOUTH LONDON

Andy Jones SE6 020 8690 1360

Jonathan English SW12 020 8673 3092

SUFFOLK

Anna Morling Leiston 01728 830574

WEST LONDON

Dee O'Dell-Athill W10 020 8960 6726

colin@odell-athill.demon.co.uk

WEST MIDLANDS

Linda Bowman Birmingham

0121 766 6611 ext 4332 or pager 0027

WILTSHIRE & DORSET

Bernadette Monks Salisbury 01722 327388

YORKSHIRE

Neil Anderton Leeds 0113 258 2740

Sue Appleyard Huddersfield 01484 311334

Continued from page 2

hard to write. Up until now, I've always contributed upbeat, positive stories to *Roar!* - partly for my own sanity (if you say good things loud enough and often enough, surely they will happen?), and partly because during the bad times, I liked to read success stories. But after a heart-to-heart conversation with Morag, she asked me to write a piece that laid my soul bare; something that explained how I went a

little nuts for a few years.

So here it is - hard to write, and probably hard to read. Is there a happy ending? Of course there is - I'm fitter and stronger than I was with colitis, and earlier this year, I had a baby, which is just the most wonderful thing in the world. I wish I could say that I'm a better person than I was five years ago, but the best I can offer is that I'm back to the old me again, just a bit more jagged around the edges.

Making Contact

Sandra Davis would like to talk to other Koch pouch owners. Her pager number is 017654 548431

Maura Hubbard would like to talk to any woman with a pouch who has had any difficulty in getting pregnant or any experience of IVF treatment. Her number is 020 8658 4017.

Contact the Red Lion Group

CHAIRMAN

Brian Gaherty
16 Hill Brow
Bearsted
Maidstone
Kent
ME14 4AW
Tel (home): 01622 739034
Tel (work): 020 7213 5679
E-mail: gaherty@bigfoot.com

VICE-CHAIRMAN

This position is currently vacant.
Anyone interested in applying should contact the secretary, Inez Malek (address and telephone number on this page).

SECRETARY

Inez Malek
33 Trevor Square
London
SW7 1DY
Tel: 020 7581 4107
Fax: 020 7584-0675

TREASURER

John White
44 France Hill Drive
Camberley
Surrey
GU15 3QE
Tel: 01276 24886

LIAISON OFFICER & NEWSLETTER CO-EDITOR*

Morag Gaherty
Address, e-mail and home telephone number as for Chairman.

SOCIAL SECRETARY

This position is currently vacant.
Anyone interested in applying should contact the secretary, Inez Malek (address and telephone number on this page).

PRESS OFFICER

Christopher Browne
3 Manor Court
Manor Road
Twickenham
TW2 5DL
Tel (home): 020 8894 1598
Fax: 020 8755 4816
E-mail: chrisb@fdn.co.uk

CLINICAL NURSE SPECIALIST

Julia Williams
St Mark's Hospital
Northwick Park
Watford Road
Harrow
Middlesex
HA1 3UJ
Tel (work): 020 8235 4110

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Phil Smith
59 Frensham Road
Southsea
Portsmouth
Hants
PO4 8AE
Tel: 023 9236 5851
E-mail: photoga@freenet.uk.com

NEWSLETTER CO-EDITOR (DTP)*

Tim Rogers
64 White Lodge Close
Sutton
SM2 5TP
Tel: 020 8661 7778
E-mail: etimbo@bigfoot.com

FUNDRAISING OFFICER

This position is currently vacant.
Anyone interested in applying should contact the secretary, Inez Malek (contact details above).

* contributions to the newsletter should be sent to Morag Gaherty

PRESIDENT

Professor John Nicholls

PATRON

Claire Rayner

Join the Red Lion Group

- Quarterly newsletter with all the latest news, views and events
- Membership is £10 (free for hardship cases and under 16s) per annum
- Write to Liaison Officer at the address above for a membership form

Write for Roar!

Have you had any interesting or amusing experiences that you think other people with pouches might want to read about in the Red Lion Group's newsletter *Roar!*?

We are particularly looking for pouch-related articles, but we are happy to publish practically anything.

Perhaps you've taken up a new hobby since having your pouch operation? Or are there any clever lit-

tle tricks or diet tips you've picked up that you'd like to share? We'd even be willing to publish an article about why having a pouch was a bad idea.

Even if you've never been published before please send us something.

You'll get the satisfaction of seeing your name in print and you may give hundreds of fellow pouch people an insight into an aspect of their

condition they hadn't noticed before. Most important of all you'll make the life of the newsletter editor a little bit easier.

If writing articles isn't your scene we are looking for other things too, including cartoons, crosswords and jokes.

With your contribution we can keep the newsletter bursting with life and make reading about pouch issues fun and stimulating.

Don't forget to look at the Red Lion Group website on the internet:

WWW.RED-LION-GROUP.MCMAIL.COM/