

# ROAR!

**ISSUE 27 • AUTUMN 2003**

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



## 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

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### BERKSHIRE

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### CAMBRIDGESHIRE

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### DERBYSHIRE

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### DEVON

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### EAST SUSSEX

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### LANCASHIRE

Joan Whiteley Clitheroe 01200 422093

### MERSEYSIDE

Blanche Farley Liverpool 0151 924 4282

### NORFOLK

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### NORTHAMPTONSHIRE

Cynthia Gunthorpe Kettering 01536 482529

David Smith Northampton 01604 450305

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### SOUTH LONDON

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### WEST MIDLANDS

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Bernadette Monks Salisbury 01722 327388

### YORKSHIRE

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Sue Appleyard Huddersfield 01484 641227



## A Pouch Goes Walking

Tony Foxell rose to the challenge of a positive article for this issue. Don't think that lets the rest of you off the hook!...

When I walk, I feel healthier for the fresh air and exercise and I enjoy the countryside through every season. Perhaps you walk on your own or with family and friends or your dog. I often walked on my own, as I wondered how my pouch would behave if I walked further with others.

Then I joined my local walking group a year ago and took the courage to meet up on Sunday mornings with fellow walkers. I started with a gentle five mile amble on the level and now I am more adventurous, choosing slightly longer and hillier treks. I choose the half day walks that usually start and finish at a pub, which is handy for the toilet and a lunchtime drink and snack with my new friends.

The Ramblers Association website or libraries have details of walking groups near you. They can send you their latest programme, you can choose a walk you feel comfortable with, and off you go.

My local group newsletter gives details of every walk with its length and any hazards like steep hills, muddy paths or stiles, so I can choose walks which are suitable for me. I've found the leaders match the pace to the

slowest walker who can catch their breath after each hill!

I find walking more enjoyable now I have a comfortable pair of boots, breathable clothes and walking poles. I find one walking pole is wonderful to ease the strain on my knees

am alone with my fifteen year old pouch, as I meet people with other medical needs who also benefit from walking. I now visit more remote places in the countryside than I might try to visit by myself.

As a pouch owner, I find it helpful to eat a light breakfast and to empty my pouch before leaving home, and then take water to drink on the walk. When I reach the pub afterwards, I feel safe to enjoy a drink and a light meal!

I've yet to rise to the challenge of a day's trek, but I am working up to this gradually, and I shall see how my pouch performs. The walking group keeps me motivated to come out for walks regularly and not make excuses, especially if it is raining, or during the shorter winter days.

You can find your local Ramblers

and pouch, but I know two poles would be better than one, if I didn't feel too embarrassed to be a forty-five year old with two sticks!

I enjoy making new friends. In a group I meet like-minded people whether I want to chat or quietly enjoy the countryside. I don't feel I

Association group on the internet at [www.ramblers.org.uk](http://www.ramblers.org.uk). I have found Walking for Health by Dr William Bird and Veronica Reynolds a useful book. If you are local to west Kent, you may like to contact me for local walking information on 01732 456490.



Don't be  
left out!

Red Lion Group  
Information Day  
and AGM

Saturday 24  
April 2004

## Long Tall Sally

Sally Jenkins ponders her new, improved life...

Asked how having a pouch for the past 6 years had improved my life, I had to stop and think, as it is not something I have reflected upon. The reason - I have been so busy living my new improved life!!!

In brief I am 38 and suffered from severe ulcerative colitis for 5 years before electing to have a pouch in a two stage operation six years ago.

My life has improved in three main areas.

Medically speaking I

- No longer take up to 18 tablets a day in fact on a day to day basis I take none.
- I no longer end up staying in hospital a couple of times a year for IV steroids.
- The aches and pains in my joints have gone.
- I no longer have regular "investigations" with frightening long instruments. You know you're in trouble when an NHS doctor says "what sort of music would you like to listen to Sally?"
- My surgeon has just said "I do not need to see you for two years unless you need me and then I am here for you" This is after 12 years

of monthly, six monthly or annual checks and we have become quite good friends.

- I have gained a huge respect for the NHS and the work they do in these difficult times.



On a social level I

- Am no longer incontinent, which was a bit unsociable if you ask me.
- I do not have to queue jump in the loos and give rambling excuses for my rudeness.

On a personal level I

- Am free to get up in the morning, eat my breakfast and go out without worrying whether there is a loo on the way to my destination.
- Feel generally fit and healthy.
- Can indulge my passion for Thai green curries preferably eaten in Thailand.
  - Stood among 125,000 other people at a Robbie Williams concert recently and did not have to worry about whether I could get to the loo in time - he was fantastic.

Wanting a family was one of the main factors that helped me to make the difficult decision to have surgery and my husband and I are very lucky to have an enchanting (most of the time) 20 month old daughter called Anna. An advantage of all my previous surgery was that it made an elective caesarian seem like minor surgery.

My digestive system and pouch are not perfect, sometimes they seem to have a life of their own and I occasionally take medication but if asked would I go through all the surgery again, my resounding reply has to be YES.

## Reasons to Be Cheerful

In reply to my pleas for a more upbeat message, Susan Walls had this to say...

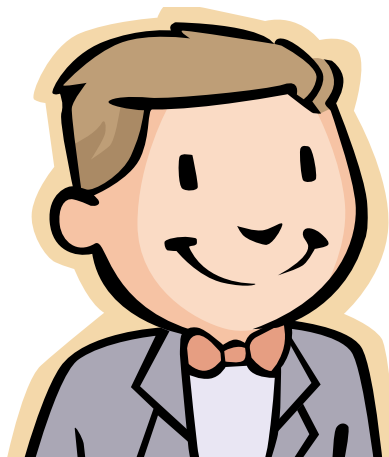
1. I am 43 years old. I can run, jump dance and laugh. A hundred years ago, ulcerative colitis would have killed me.

2. My innards are all back inside me. Fifty years ago, I'd have been stuck with my innards as my outards. Only the Pompidou Centre looks good with its plumbing on the outside.

3. Full-blown pouchitis isn't fun, but it's ten times more fun than full-blown ulcerative colitis.

4. Pouchitis can be your friend - think of it as a guru in a white dress. It will tell you when you're not living a good life: time to stress less, or get more rest.

5. Three years ago, I gave birth to



a lovely baby boy, despite the reduced-fertility statistics for women who've had a pouch operation.

6. Since I had Sam, my life has improved immeasurably because a) he makes me laugh a lot, and b) all my new friends have bathrooms stocked with Sudocrem and baby wipes.

7. Twenty years ago, there were no baby wipes.

8. I never get constipation.

9. I'll never need colonic irrigation.

10. I don't get premenstrual bloating.

11. I never liked Bran Flakes anyway, but I love white bread and pasta.

12. Every year my pouch behaves better than the year before. By the time I'm sixty, I'll be superb!



## A View from Four Kilometres Up

Chris Browne chooses an unusual holiday destination.

Flopping out on unspoilt beaches, endless fun and games in the sun and two-week tours through fine scenery are how we usually get away from it all.

And why not? After all, we deserve a break from the other eleven months of unceasing toil, trains and troubleshooting.

Then there are activity holidays. Some of us enjoy a more athletic type of break, happy to tire ourselves out through sheer energy and enthusiasm.

Though I've checked out a few of these before, I've never actually gone on one as I find trying to keep fit the rest of the year quite enough without having to go away to do so.

But, gentle and hopefully untired readers, all that changed when I read some brochures about Peru. Spectacular peaks, lakes, plateaux, tropical rainforests, the Amazon jungle, and finally the Inca Trail and the ancient city of Machu Picchu. Who could resist? Not me. So I signed up.

"You're not a wimp after all," emailed Malika, my favourite niece from the Himalayan foothills near Kathmandu, her home for the past 12 months. "And as if there were ever any doubt," I replied defiantly.

Our party of 10 flew to Lima, the Peruvian capital, via Miami. An incident-free trip except most of the world seems to land at Miami airport at once a huge, heaving mass of people scurrying to and fro as they try to find the Right Connection.

In the Miami morass, I managed to lose my favourite paperback and a sweatshirt. But then one man's loss is another man's gain, as the old saying

goes.

After 16 hours' flying we reached Lima, a surprisingly colonial city, where we later toured some seventh-century excavations, visited the cathedral and settled down to a meal of boiled guinea pig, a local delicacy, and guava juice.

Our next stop was Cusco, the former capital of the Incas. It has more tourists than Brighton, Blackpool and Berwick-on-Tweed put together, but is surrounded by rugged 3,000 metre high crags, mountains and lakes and excited groups of kite-flying children.



But I was condor-spotting. Seeing this Andean vulture with its three-metre wingspan is unusual it lays only one egg at a time and thus contributed to its own near-extinction though one of our party reported seeing one soar around a snowy peak.

The Peruvian guide was irrepressible. She made us play games of touch rugby and hide-and-seek and told us she was a direct descendant of Pachacutec, the warrior-king who started the whole Inca thing in 1438. She said they built their fortresses, windows, steps and altars in threes

and facing east. A great bunch of people really. Perhaps I'll turn my house round to face east and plant three large shrubs to greet future guests.

But back to our story. During the next three days we visited Incan remains in Pisac and Chincero and followed cascading street markets of alpaca rugs, hats, scarves, sweaters and gloves and a slightly tourist-conscious witch-doctor who strutted his stuff in technicolour robes, handing out prescriptions to startled passers-by.

Then, in the finest of British traditions, we settled down to a pot or two of tea made from coca leaves. It tastes like green tea and helps stave off AMS (acute mountain sickness). So some of us had five cups or more. Its more sinister derivative is cocaine.

It was time for the Great Hike. Five of our party went by coach to the start of the Inca Trail at Coriwayrachina (it means gold-sifter, though there's none left), a valley spanned by a suspension bridge. We were joined by a couple from New York and two super-fit Spaniards, each of us paying a small sum for the trip and a tour of Machu Picchu.

We set off with a guide named Julio and 12 porters, who carried our overnight gear and cooked nourishing meals. I seemed to hit it off with the American pair so we three set off at a brisk pace on our way to the first campsite. We climbed about 12 kilometres, the main group following behind us, and after a meal of soup, pasta and several bottles of beer, settled down contentedly for the night.

It was a false dawn. The next day

was torture. That morning we climbed 1,200 metres from 3,000 m to 4,200 m and then lolloped all the way down the other side in the afternoon. As I am a pretty fit fiftysomething, I was again one of the leaders. Some of those rocky clefts and crags would test the mettle of a London marathon regular, and I felt considerably better when the American girl called me her rock-star.

We found downhill can be as tricky as uphill, and at least two of our party struggled with air sickness even when they were going downhill. It meant the faster ones had a long wait for their next meal.

The views were awe-inspiring snowy peaks, Incan trails and sudden hot, humid patches of tropical rain-forest. I got my wish of seeing a snake as it peered over a yellow bough, though I was too exhausted to comment at the time.

That night we all reached our own little Everests. The following day was a milder but longer version of the second. At the halfway mark, we toured a mountain fortress and admired the Incans' peerless stonemasonry walls that had withstood two of the world's fiercest earthquakes in the last three hundred years.

Finally, on the fourth day, a jubilant collection of Australians, Germans, Swiss, Americans, Spanish, Mexicans and English made a 4 a.m. start from the last campsite on our final ascent to Machu Picchu.

Our early beginning meant we were able to see the Incan city silhouetted against the rising sun. Suddenly all those other-worldly pictures from the Discovery Channel and Geographia magazine became real-worldly.

We spent the day exploring the array of temples, houses, burial sites, altars and symbols of pumas, condors and snakes the Incan gods of earth, spirit and brain. Rock-solid and intact, Machu Picchu was untouched by the Spanish conquistadors when they invaded in the 16th century. And the rest, as they say, is history.

I'd visit Peru again and again and again, and if you're reasonably healthy, you should too. It's not that expensive and you might find the flights more punctual than the average rail trip to the Lake District or the Norfolk Broads.

## My Story ... by Marion Silvey

Marion Silvey tells us what a positive impact her pouch has had on her life

1992 was the year I had my pouch – 18 November to be precise. Can any of us forget the date of such an occasion? Unlike the majority, I had my pouch in a one stage operation, under the brilliant hands of Mr Thompson at Gloucester Royal Hospital.

I had been ill with Ulcerative Colitis for 17 years, getting progressively worse.

In the end, the steroids were making me feel even worse than the condition they were treating.

There are only three good things I have to say about steroids.

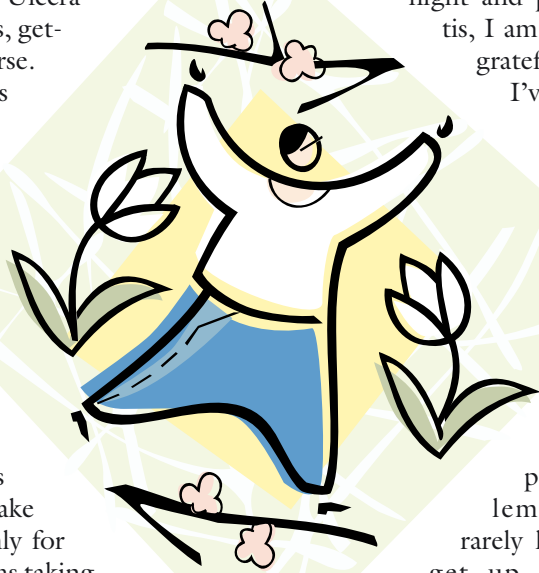
1. In the early years they did always make me better, but only for the time when I was taking them.
2. They made me hyperactive. I thought nothing of doing housework and ironing at 11.30 at night, I just wasn't tired. I'd be up at 6.30 am off again! This is someone who normally needs a minimum of eight hours sleep a night.
3. Through the coldest of weather, I was always hot. We saved a fortune in heating bills. Normally, I'm the first to put the central heating on at the end of the summer and the last to turn it off in the spring – or possibly summer! I have the chair nearest to the fire and still my feet rarely rise above freezing.

However, I digress. My operation. It was traumatic, there's no getting away from it: it is major surgery. I was in hospital for two weeks. The first two weeks at home were very difficult. Miraculously, one day I turned a corner. I was delighted to be able to eat a proper Christmas dinner, albeit a very small portion.

From then on I never looked back. I had a check-up after three months and was signed off from the hospital. I've never taken anti-diarrhoea tablets – my own view is, I've

punished my body enough with drugs (prescription drugs I hasten to add!) and avoid such things wherever possible.

Listening to other people who have suffered leakages, particularly at night and pouchitis, I am indeed grateful that I've never had any



of those problems and rarely have to get up in the night. Unless of course I've eaten very late in the evening.

Yes, I do have to make some small allowances in my every day life, but it's nothing that inconveniences me or other people.

At the AGM, during the female pouch owners' discussion, it was wonderful to hear everyone laughing at some of our difficulties. We've all been stuck in the ladies waiting for someone to use the hand dryer before we can 'do the business'!

When I read the newspapers or watch the news and hear the plight of many people in this world, I don't think being stuck in the ladies for ten minutes is much of a hardship.

My pouch changed my life and I shall always be grateful for medical science and the skill of my surgeon.



## Editorial

Many thanks to those of you who contributed to this month's issue of *Roar!*, on a variety of topics. As you can see, we have given out a couple of prizes (selected entirely at random, not an indication of literary merit or other value, I hasten to add) to two of our contributors. We have further prizes to give out in future issues, as explained elsewhere in the newsletter. So please get your pen or mouse out and send me something. If you could e-mail it rather than sending in a hard copy, this would help enormously.

Christmas is approaching fast, even as we continue to swelter in the remnants of a hot summer, and before you know it, we'll all be sending out Christmas cards. We have chosen not to include a merchandise list in this copy of the newsletter, but if you think you might be interested in our Red Lion Group "festive season" cards or any of our other merchandise, please feel free to contact our Secretary Christine Lawton to find out what is available and at what cost. Our cards are likely to be completely redesigned for next year, so if you like the lovely colourful lion cards, now is the time to get hold of them, while stocks last. They will be £3 per 6, including postage. If you're on the Gaherty Christmas card list, though, you'll be getting one from us, so you won't miss the cheerful picture!

Let me draw your attention to the new Question & Answer page being written by our pouch nurse specialist at St Mark's, Joanna Sweeney. She is keen to tackle the pouch issues which concern you, whether you want to know what to expect after surgery or how to help yourself to a better pouch. I'm sure there are many more things you can think of to ask. Please make the most of her expertise by e-mailing

or calling her with your queries.

I'm very pleased to offer you a free "orange alert" card with this issue, which might well prove useful the next time you need to use a toilet urgently when out and about. Many thanks to Dansac for producing this extremely handy and discreet little item. I know many people will be nervous about presenting this card to other toilet users when trying to jump the queue for legitimate reasons. If you have any experiences, good or bad, about using the card, please do send them in. Hopefully this will offer reassurance to others about its value to them. There's no point carrying the card about unless you are prepared to use it when Nature calls and rings insistently on the doorbell!

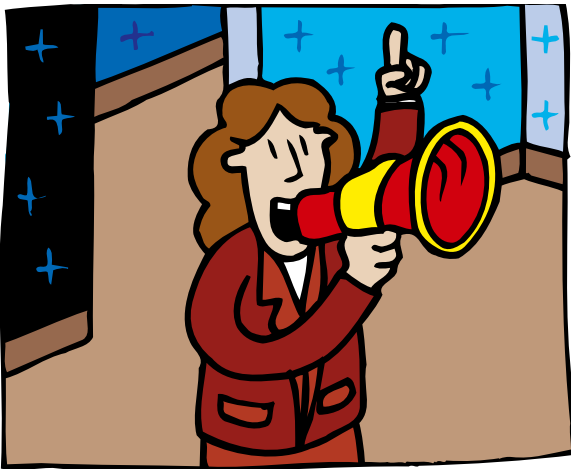
We'll be in touch before Christmas with a separate mailing regarding renewals for next year, including an opportunity to complete a gift aid form, which is an extremely valuable (and free!) way for the Red Lion

Group to raise funds. If you are a UK taxpayer, please do help us to claim this money which is available to us. Also, it does help us hugely on the adminis-

tration front if you pay your subscription by annual banker's order, and from your point of view your subscription is renewed automatically. That form also will be included in the mailing, so please consider completing and returning it. If you have any queries about the banker's order or gift aid forms, our Treasurer John White should be able to help you.

Anyway, enjoy the newsletter and help us to make the next issue even better. As usual, full contact details for all committee members can be found on the last page of the newsletter.

*Morag Gaherty*



## Prizes for Articles

OK, OK, I don't know why I bothered with begging and pleading last issue, when it appears we can also run to outright bribery!

Inez Malek, whose middle name should be something like Incrediblywellconnected, managed to secure some fantastic prizes for the Information Day in April. They were so good, we couldn't exactly give them away, ten a penny. Instead, we decided to keep some as prizes for contributions to *Roar!*

This issue, we have given away two prizes of a signed paperback copy of a book by Una Mary Parker each to Susan Walls and to Sally Jenkins, for their articles.

For future issues we have the following prizes to give away:

- £20 Boots voucher
- 2 children's tickets to **London Zoo**
- 2 tickets to **Courtland Galleries** (without catalogue)
- 2 one day passes to **LA Fitness** London SW7
- Day Membership for two at **The Berkeley Health Club and Spa** in Knightsbridge before the end of March 2004
- Lunch/Dinner for two at the **Moa Tai** in Chelsea or Parsons Green
- 4 signed paperbacks by Una-Mary Parker

These prizes are of pretty high value, but I appreciate that they are largely London-based, so please give an indication of where you live when sending in material, so that we allocate them sensibly.





## Roar Quiz

What sort of pouch owner are you? Do Roar's quiz and find out how you're coping with your brand new organ.

1. You make a new friend, someone you think you might see a lot of. Do you:

a) Tell her straight away about your operation and your pouch – she needs to know what a fascinating and differently-plumbed person you are.

b) Tell only if the subject comes up.

c) Say nothing at all, ever – nobody else needs to know about your private bottom business.

2. If do decide to tell your new pal, do you:

a) Explain how you nearly died from a life-threatening disease involving blood and pus and outrageous fevers. Describe how you were rushed to hospital and disembowelled on the spot. The operation was so long and complicated that the surgeon had to take a Cotswold mini-break in the middle of it.

b) Explain your condition in a straightforward way.

c) Say you have a 'bit of tummy trouble'.

3. You get a bad dose of the squits with some bleeding and fever. Do you:

a) Panic, cry and throw yourself around in a dramatic fashion.

b) Drink some electrolyte mix and rest for a day, and if that doesn't work, take a course of Cipro.

c) Ignore it, it'll go away.

4. You are asked out to dinner, in the middle of a bad bout of pouchitis. Do you:

a) Give your would-be host a blow-by-blow account of your terrible symptoms. Of course you can't come, you're dying here!

meal, you have to spend a long and uncomfortable time in bathroom. Do you:

a) Describe in technicolour detail the splatter-fest that was your trip to the loo. (After all, you don't want your fellow diners thinking you're bulimic!)

b) Say, sorry about that, feeling a bit ropy tonight. Then carry on as though nothing had happened.

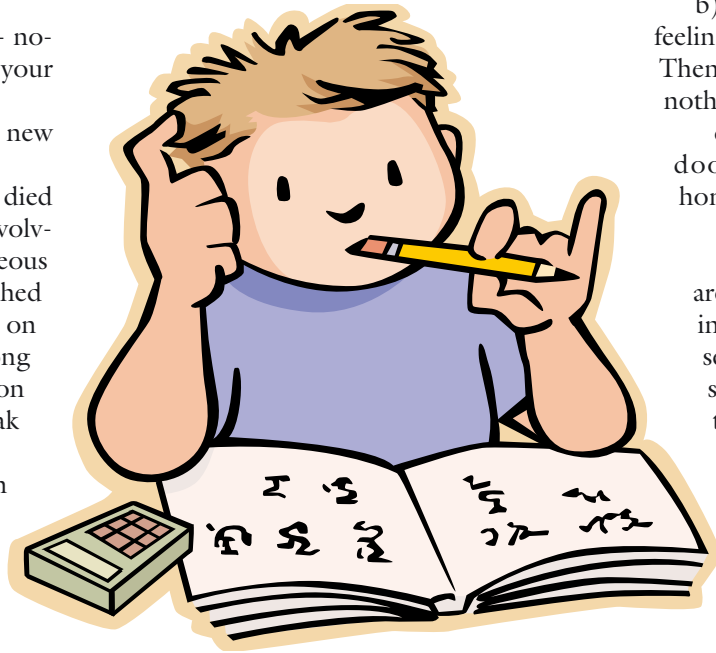
c) Slip out the back door and go straight home.

Let's see how you did:

*Mostly A's:* My, you are enjoying having an interesting disease. You see your life as an episode of ER. You need to get over this. Spend some time doing charity work or ask to help on the hospital library. There are people out there having a really terrible time.

*Mostly B's:* You have a healthy approach to your illness. You should run a workshop to help the kind of people who got mostly A's.

*Mostly C's:* You are in denial. This isn't good. If you carry on like this you will implode.



b) Say, could we make it next week?

c) Make an excuse – your cousin is visiting from Alaska.

5) You go out to dinner at a close friend's house. In the middle of the

## The Alert That Won't Hurt

Chris Browne tells us all about this issue's "valuable free gift". Unlike most magazine freebies, this one really is worth having, at least for pouch owners...

You've heard of the Red Alert. It's a public call to be on your guard during an emergency or bomb scare at an airport, rail station or public building. Well now there's an ultramodern version called the Orange Alert.

This too is a warning signal, but it's a much more personal one and one we will all find useful during those long, lingering waits at parties, parks and on planes.

The Orange Alert is in fact a small plastic card that you can use whenever you're about to be caught short. You just take it out of your wallet or bag

and show it to an official or fellow queuer at a disabled loo or public toilet.

If they are sympathetic, which they usually are, it will work its magic and you'll not only get priority but also considerable relief.

The card, which is made by Dansac the medical equipment suppliers, is sent to stoma-nurses, hospitals and support groups like us. And the good news is you'll be getting your own free version with this issue of *Roar!*

So next time you face an Orange Alert you'll know what to do as well

as saving yourself an agonising wait and an embarrassing moment or two.



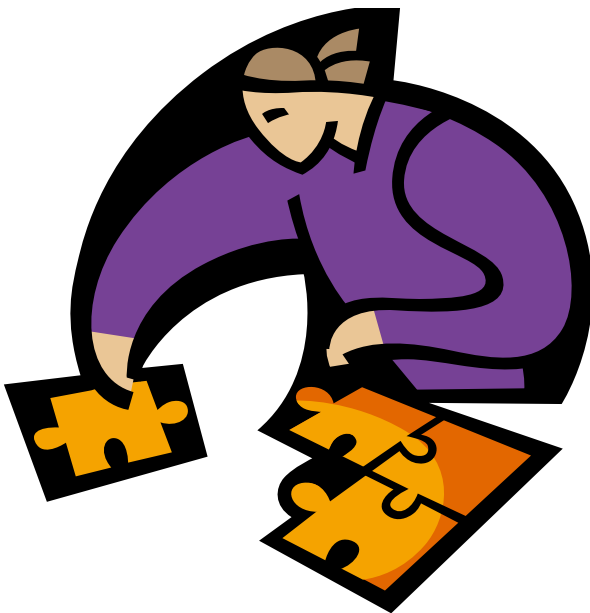


## Letters

*Dear Editor*

I'm writing, very belatedly, to say how impressed I was with the April Information Day at St Mark's. I thought the speakers were excellent and it was reassuring to know that so much work is being done to help us and our pouches. It was also one of the only conferences I've been to recently (and I go to quite a few with work) which stuck to the timetable. Big thanks to all concerned.

However, it was a sad day for me. My husband and I have been trying to conceive for the last couple of years but when nothing much was happening it didn't surprise me – I'd picked up from various sources that having a pouch could sometimes mean conception was a bit difficult. Imagine my horror then to hear Prof Nicholls say that he believed women who hadn't started or completed their families should always be advised to stick with an ileostomy until they had done so. News to me!



After 3 years of UC, I had a 3-stage pouch between 1998 & '99. I was in my early 30s, wasn't married and hadn't had children. Over all that time and hospital visits, pre and post-op, nobody ever mentioned the subject of fertility. It just didn't come up and I, being considerably less informed then than I am now, didn't think to ask.

Events have moved on. In May, I went into hospital with a severe right

hand side abdominal pain and high temperature which I put down to my pouch or bowel. (Don't ask me why, it's just that I've got so used to tummy pain caused by UC/pouch, I've never assumed it could be anything else).

To cut a long story and a 2½ week stay in hospital short, it was an ovarian abscess the size of a large plum. Once discovered, it was removed very quickly along with my right ovary and Fallopian tube which came away in the consultant's hand. Apparently, the abscess is likely to have been caused by all the obstructions and damage done to my tubes/ovaries during pouch surgery.

My left hand tube is also damaged and my left ovary is stuck to my pouch, but they couldn't do anything about that when I was in theatre as I'd only consented to right hand side stuff. So.... I'm now left with the prospect of the same thing happening again on the other side. I've waved goodbye to the prospect of having my own children and without wanting to be ungrateful, I feel cheated and robbed (and incredibly sad). After a lot of thinking, I've decided I'm not prepared to go through IVF on a dodgy ovary which is stuck to my pouch.

I know at our Information Day Dee gave a very upbeat talk in the presence of her beautiful children, but I think I'm the flip side to that. My point of writing this letter is to suggest to any women who may be thinking about pouch surgery and who want children, to consider the possibility of their fertility being affected. I'd got so used to my ileostomy, another couple of years or so with it, then the pouch op after children, wouldn't have made much difference to me.

I also hope that Prof Nicholls' views reach a few more pouch surgeons so that some of them sit on the side of the hospital bed for a chat before wielding their knives! It might save someone the heartache I've been through.

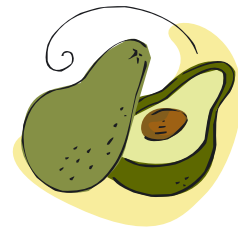
*Philippa French*

*Dear Editor*

Around 1998, I wrote to *Roar!* seeking some answers to a problem I have with burning, on evacuation of my pouch. You printed the letter under the heading "A Burning Issue".

I was very heartened by all the replies, but none of the suggestions worked for me. Since then, I have cut out red meat and strong cheeses from my diet, and this has helped a little.

However, recently, I found quite by accident that eating a couple of slices of avocado pear eaten before



lunch and the main evening meal has eliminated the burning, and also seems to change the composition of the waste, so that the evacuation process is much easier.

I have been doing this for about a month now, and I am quite convinced that this is the answer for me. I would like you to pass on this tip to fellow pouch owners, and it maybe helpful if placed on the website.

I realise that avocado pear is quite expensive, but a medium sized one lasts 2 – 3 days and is well worth the expense.

I would also be interested to hear from any experts out there just what properties it contains, to have this magical effect on the enzymes responsible for the burning. I also know that it has a high fat content, but have been told that it is a non saturated fat.

*Rosemary Tilley*

*Ed note: This is especially interesting, as anecdotal information I have gleaned from working with children who have suffered nappy rash is that avocado can sometimes exacerbate or create this rash, which seems to be almost precisely the opposite effect from the one Rosemary describes. It just goes to show how foods can affect people very differently, so don't all rush out and buy tons of avocados until you check whether it is a help or a hindrance for your own situation!*

## Question and Answer Page

**Question – I had surgery for ulcerative colitis 2 years ago where I had my large bowel removed. I am now waiting to have the ileo-anal pouch and eventually reversal of the stoma. How much time will I need to take off work?**

*Answer part 1 – Returning to work after ileo-anal pouch procedure and formation of loop ileostomy*

The ileo-anal pouch procedure is a major operation involving a midline incision or laparotomy through the abdomen and hospital stay is about 7-14 days. You will also have formation of a loop ileostomy which will be in the same position on your abdomen as your previous ileostomy but it is formed from a piece of small bowel higher up the gastro-intestinal system. As a result you may find the output from the stoma is higher and of a more liquid consistency. This can sometimes result in dehydration and difficulty with weight gain in the initial stages of recovery.

Your abdominal muscles will take up to six weeks to heal so it is advised not to take part in any heavy lifting, household chores or driving during this period. You will be seen in outpatients for a post-operative check-up in 6-8 weeks following surgery so it is

probably advisable to wait for this before returning to work.

You need to think about the type of work you do e.g. heavy manual work or office work. Consider working part-time or from home if this is possible with your job. Remember that when you commit to returning to work, in most jobs their expectations of you may be the same as before you had your operation.

After your post operative check you will be put on the theatre list for reversal of the ileostomy. This usually takes about 12 weeks following surgery. Realistically, many people do not go back to work between the pouch procedure and reversal of the ileostomy or if they do it is generally on a part-time basis

*Answer part 2 - Returning to work after closure of the ileostomy*

This is a smaller operation, as it does not involve a laparotomy or midline incision through the abdomen. An incision is made around the ileostomy and the bowel is then closed. Hospital stay is about 4-7 days and although it is a smaller procedure you still need a minimum of 4 weeks off work. After 4 weeks you can decide if you are ready to return to work.

Many patients recover very quickly

physically from this procedure; however, it is the psychological and social issues which may take longer to recover from. You may need time to get used to how your pouch is functioning, what it feels like, titrating medication such as loperamide and establishing a healthy diet that works for you. It also takes time to build up confidence in the functioning of your pouch and your general health. If you have been unwell for a long period you need time to realise that you can resume a normal healthy life.

**Question – I have just had closure of my ileostomy. Before my surgery I was very fit, going to the gym 4 times a week. Can I resume this same level of fitness?**

**A –** Yes. You need to allow yourself at least 4-6 weeks to recover from this surgery before doing any strenuous exercise, especially on the abdominal muscles. After this time you can build up the amount of exercise slowly, but you must be sensible, gradually building up the amount of exercise you do.

*Please send the questions you would like answered to Joanna Sweeney, Clinical Nurse Specialist of St Mark's. Her contact details can be found on the last page.*

## Jottings from the Treasurer

Some of you may be wondering "Who is this person who controls the funds of the Red Lion Group?". John White would like to tell you more about himself.

I was an administration manager in the National Westminster Bank and in 1983, three years before I was due to retire from the bank, I was seconded to St Mark's Hospital in City Road, London. There I was to be administrator for the 150<sup>th</sup> Anniversary Appeal which hoped to raise £1,000,000. I was also to be administrator for the St Mark's Research Foundation. The bank continued to pay my salary and St Mark's got me for free.

My life changed dramatically and this job was far more interesting than banking. I came into contact with so many people, doctors, nurses, hospital staff, patients and relatives of patients. When I retired from the bank

in 1987 I thought well I'll have to do something so I decided to stay on at St Mark's, where I remained in my posi-



tion until June 1991 when I had to undergo open heart surgery with a double bypass. Caused I might say by stress in the bank and not St Mark's.

I did go back in September but found the travelling too much so retired (again!) in February 1992 when I was 65. I had become treasurer of the Friends of St Mark's in 1989 and remained in this post until 1997. So I still kept my links. I am also an associate member of NACC, and PINNT both organisations whose roots were created at City Road. I joined the Red Lion Group in 1997 and became treasurer in 1999. So as you can see I just can't give up my association with that marvellous specialist hospital. Oh yes, we did make just over the million pounds but it took about 7 years. I have been wondering whether I should lay down my pen (or should it be mouse in this computer age?) but I



will see how I go. It gives me something to do and can be done from home, so unless someone else would like to take it on I will stay as long as I am able. *[Ed note: thank heavens for that!! You didn't think we would let you go quietly, did you John?]*

I would like to say a big thank you to all those members who have made donations. Especially to Martin Spencer who ran in the London Marathon in aid of ourselves, the Dunmow Football Club who I believe Martin is associated with, and to a very generous relative who wishes to remain anonymous. It is very gratifying to be able to claim tax back via the gift aid scheme and thank you to all who have signed the forms. This year I hope to claim back £397 and I will always send you a form if you would like one. Don't worry if you have already signed one as I keep the original. If you sign one now I can claim on all monies subscribed since April 5th 2000 so please consider it.

John White

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[www.redliongroup.org](http://www.redliongroup.org)

## The Convenience Connoisseur

Susan Walls thinks about toilets. A lot.

I am obsessed with toilets. I dream about them. And not always in a good way.

It's been building up for a long time: five years with ulcerative colitis, and cystitis. Then a year as an ileostomist (I hate that phrase – much prefer 'person with a bag of poo strapped to her tummy'). Followed by seven years as a person with a pouch of poo stapled to the inside of her bottom, and pouchitis.

Add it all up and you've got a toilet obsession bordering on the slightly mad. Most people have stress-dreams about failing their maths exams, or turning up to work naked. I dream that I can't find the toilet, or that when I do, it's completely disgusting so I can't bring myself to use it. Something like a French toilet *[Ed note: which the French call Turkish toilets ... nothing to do with them at all]*.

Which brings me to the point of this article. I used to have a (completely racist) theory that cars characterise a nation. You must have noticed that there's a resolute, Prussian sort of air about a Volkswagen. Japanese cars are efficient but all look the same. French cars are stylish but temperamental. Spanish ones won't work after lunchtime...and so on.

But lately I've transferred the theory to public toilets – and it works so much better.

Consider French toilets. Only a nation of supremely arrogant individuals would design something like the pissoir. There you are, walking along the road, minding your own business, and you're faced with the sight of a strange man doing a wee. Granted, bits of him are hidden by the steel surround, but you can still see enough to work out what's going on.

Why do they do that? And that hole-in-the-floor thing they have in rural France – what's that all about? It's as if they're taunting you: "Whassammater weeth yew, yew beeg Eengleesh seesy. Dew yew nut like ze flies? Duz eet steenk? Are yew nut tuff eenuff to sheet ze French way?"

Well no, actually.

Dutch toilets are polite and cheerful. My favourite toilet in the whole wide world is in the Beehive depart-

ment store in Amsterdam. No frills or silly dried flowers – just a clean, pleasant-smelling, prettily-appointed room with a pale lilac glow to it. So very Dutch.

And my friend who owns a villa in the south of Spain tells me that the local public toilets are ornately tiled and beautifully maintained – as proud and handsome as a Flamenco dancer.

British public toilets are like our public services: shabby and out of date. But I have got a soft spot for the old Victorian ones in the middle of traffic islands that smell of carbolic. There's something of the lost empire about them.

And don't get me started on American public toilets. There are many good things about the American people, but they do have some annoying traits – and many of them are reflected in their public toilets. Americans are puritanical to the point of lunacy. So they call their toilets rest rooms, or – at a push – bathrooms. I asked one American why they don't say 'toilet', and she looked horrified and said "We don't need to know what you're doing in there." So every time you go to the loo, Americans like to think you're having a rest or taking a bath.

Anything else is too terrible. And you don't buy toilet rolls in the US, the polite term is 'Bath Tissue', which is presumably what you dry yourself with every time you go to the loo for a quick bath.

Then there's the flooding-and-blockage problem. American toilets don't work very hard (just like the people, who spend a long time doing not very much, and then claim to be exhausted).

So public loos make a great show of being 'have-a-nice-day' and posh and clean, but behind the shining tiles and fragrant disinfectant, the plumbing is rubbish. All style and no substance.

The Germans on the other hand, have efficient toilets that just quietly get on with it. And the best bit is: there's a special shelf in the bowl to collect poo, so you can inspect your out-goings before flushing. Which is as reliable and straightforward an idea as...well, as a Volkswagen camper van.

## Piling Off the Pounds

Tim Rogers describes how he lost 33 pounds over the summer safely.

I am sure that most post-colonic sufferers of ulcerative colitis, whether they be ileostomy or pouch owners, would agree that life is much healthier without a diseased colon. One proof of this for me was an ever-expanding waistline after my colectomy. Urgency and losing pints of blood through my back passage was miserable, but at least I could eat as much as I liked and still look skinny as rake.

OK, I probably looked a bit too skinny. When my mother visited me in hospital after my first operation she almost passed out on the spot when she saw me emerging from a bath with not an ounce of fat on me. I was a walking skeleton draped in skin. My legs didn't go straight down. Instead they stuck out alarmingly at the knees and then went back in again. I couldn't sit down without a cushion because my backside was just skin on bone: there was no padding back there at all.

So I've always been rather nervous about losing weight. However, after my final closure operation I started to develop a bit of a paunch. I was told I was looking 'affluent', which I think is a polite way of being called lardy.

Being a rugby player I did not see much problem in this. I would stoke up and reach the peak of weight and fitness at the end of the season in April and then go all flabby during the summer through lack of exercise. Needless to say I continued to eat chocolate flapjacks as though I had a game of rugby the following Saturday.

So my body was in peak condition when it was covered in layers of winter clothes, and then saggy and blobby on the beach and while walking around in shorts and T-shirt. I vowed that one summer I would actually continue exercising and try and lose a bit of weight.

Then in April I read an interesting book review in the *Economist*. The reviewer said they had followed the diet in the book and indeed had lost the weight advertised in the title. My interest piqued, I ordered a copy of the book *The Eat to Live Diet: Lose 20*

*Pounds or More in Six Weeks—Safely* by Joel Fuhrman.

At the end of the last rugby season I weighed 92 kilograms, or 14 stone 6 in real money. According to numerous health websites, and a Boots weighing machine, the ideal weight for my height is 77 kilograms, or 12 stone 2.

By following the advice in the book I found it very easy to lose 20 pounds in six weeks. The remaining 13 pounds were a bit harder and took a further 15 weeks and frequent visits to the gym. But towards the end of September I finally hit my ideal weight.

I'm sure you're itching to hear what kind of diet the book recommends. Fortunately this isn't some kind of crazy Atkins diet.

In a nutshell the book urges you to eat as much unrefined plant food as possible, and avoid animal products and fat. The idea is to fill up on obviously healthy foods such as vegetables, fruit, wholegrain bread, brown rice, pulses, beans and nuts. This will leave you less hungry because your body is getting all the nutrients it needs so you won't crave vast quantities of burgers and chips, and you're already full.

Before I continue I ought to point out that the diet may not be suitable for the majority of readers. It is unashamedly high in fibre, and I know that nuts don't agree with many pouch owners.

To give you an idea of a typical day on the diet, I will eat a bowl of muesli with soya milk—I find that Alpro is an excellent alternative to milk on cereal, although in my opinion it tastes vile in tea—followed by two slices of wholegrain toast with lashings of marmalade, with no butter. People put butter on bread because a couple of centuries ago jam and marmalade were an expensive luxury. They took to smearing butter on bread to make the thin layer of jam on top taste thicker. Nowadays with jam and marmalade easily affordable there's no reason to use butter at all. Jam is fat-free, so why not try slathering double or treble your normal quantity on bread and forgo butter or margarine? After a week or two you won't notice the difference.

For lunch I will have a whole gem lettuce, four or five cherry tomatoes, half a tin of ratatouille from Sainsbury's and a wholegrain pitta, a mountain of fresh spinach, a banana, a pear and a date for good measure. After that I feel absolutely stuffed.

If I feel peckish in the afternoon I'll have another banana and a handful of almonds. Then for supper I'll knock up some garlic, ginger, mushroom ketchup, balsamic vinegar, mushrooms, beans and a little bit of chicken with brown rice with more cherry tomatoes on the side (as you can probably tell I am very partial to cherry tomatoes), all cooked in a small amount of water, not oil. Needless to say, the book contains a host of other delicious recipes.

The beauty of the diet is that as long as you cut out all oil, saturated fat, cheese and pasta, and try to cut down on meat and fish, there are still loads of delicious foods that are good for you: think spices, garlic, ginger, chutneys, ketchups and mushrooms.

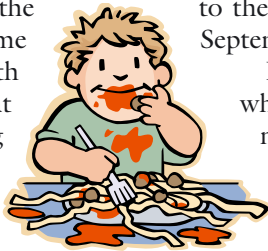
The diet does take a bit of getting used to, and I found my palette changed. I also found it useful to follow the tactic of cheating at weekends, but being very strict during the week. My weight would go up a bit every Monday, but the overall trend was steadily down.

The book is written by an American doctor who feels passionately about the unhealthy diet followed in the west. He refers to a multitude of scientific studies showing that our diet is leading millions into premature death through heart disease, cancer and diabetes.

Even if you are unable to follow the diet to the letter, I would recommend reading the book to get a sobering insight into just how bad our western diet is. Just giving up butter or margarine on bread, and refusing to eat anything containing hydrogenated vegetable oil, may help you lose several pounds permanently and add a few months to your life expectancy!

*The Eat to Live Diet: Lose 20 Pounds or More in Six Weeks—Safely* by Joel Fuhrman published by Piatkus Books.

To read about ideal weight calculations, visit <http://www.halls.md/ideal-weight/devine.htm>





## Swimming Through

Julia Peters was moved to share her 'new pouch' experiences after reading some of the tragic, painful stories in the spring edition of *Roar!*

I am glad to see such honesty and recognition that things can be very difficult after surgery; though I also found myself thinking 'if I'd read this a year ago, I'd have felt suicidal'.

I wrote to this newsletter a few years ago (My Story - My Mistakes) describing my attempt to cure my colitis with complementary therapies, ending up in a very depleted state before I finally surrendered to having the ileostomy.

After this I had a bag for 18 months; I adapted pretty well to this and was reasonably happy and certainly comfortable. But like most people I longed to be 'normal' again, and in October 2001 was admitted into hospital for my pouch operation. This proved to be a very lengthy procedure, since the two previous abdominal operations had left me with masses of adhesions to be dealt with; nevertheless I was assured all had gone well.

Perhaps I should add here that in January 2001 I'd had a minor operation to remove the severe haemorrhoids I'd developed while struggling with the colitis. It was something of a concern and an experiment for my consultant, since there would be no faeces passing through the anus, and we did not know whether it would close up.

Fortunately it all went well, but I was warned that the consequent scarring could make things 'a bit more difficult' for me. Knowing just how agonizing piles can be I had some misgivings, but I wanted the pouch badly and felt I could stick a few weeks of pain to achieve the final desired result.

I went into hospital bravely, but as soon as I arrived vivid memories flooded back of the awful two months I'd suffered there before. Matters were

made considerably worse by a complete lack of close family support. My parents wanted no contact with me (they still don't—but that's a whole different story)

My beloved 20 year old son had recently gone off to Australia for an indefinite stay with his father; and my nine year relationship had come to an abrupt end a month earlier. (Finally a happy ending there, since after six months apart we got back together, and recently married.) I did have the support of some wonderful friends, but as you can imagine, it felt a bleak and lonely time.

The hospital stay was terrible; it was a different ward to the one I was

team. Being crooked and ill placed they allowed the wound to fall apart, resulting in an opening over an inch wide at the bottom. As you can imagine this did not help with my feelings of mutilation and general insecurity.

To be fair on my loved ones, my son called while I was still in hospital to say he was coming home, and when I called my estranged partner he gladly came to stay the nights with me until Daniel's return.

Gradually time, homeopathic remedies and herbal tinctures healed the more immediate post-operative effects, but I was still left with the constant strong urging for stool. When I did go to the toilet, little was passed and it was a very painful procedure.

I was into a vicious circle of tension and pain. My

GP thought I probably had an anal fissure; my consultant put the problem down to the piles which had recurred al-

most immediately after the pouch operation.

Whatever it was, how could I hope to heal when I was passing these explosive stools day and night?

On the advice of my osteopath I began to have a cold bath, about four inches deep, every morning. I sat in it for three minutes and splashed the cold water over my abdomen. Since I started this in December, it was something of a chore, to say the least. However, it undoubtedly helped to soothe and heal this whole inflamed area, and I persisted with it for at least six months.

Shortly afterwards I joined a gym and started to swim most days. I sensed the whole anal area was toxic, stagnant and sick, and it felt important to get the blood moving through it, so that it had a chance to heal. I certainly



in previously and very badly run. On more than one occasion I found myself left for hours in terrible pain or covered with diarrhoea. Consequently, I endeavoured to get out as fast as I could, but came home to a cold and empty house. The bed was damp, I could not get warm and promptly added cystitis to my list of troubles. I constantly felt as if I was bursting to pass a stool, but found no relief from doing so. In fact, the more I went the worse this feeling became, so I resisted as much as possible.

With both sphincters giving such problems, it was hard to get any rest. I frequently did not make it to the loo and was often running baths in the early hours to clean myself up.

As if this was not enough, the wound staples had obviously been finished off by a junior member of the

could not do any other exercise at this time as my bowels were still hugely unreliable.

I had frequent accidents and even just walking to my local shops was difficult. The swimming was hence very nerve wrecking as you may imagine, and any activity had to be arranged as long as possible after eating. I well remember that year my Christmas shopping was all done within reach of the chair in my local pharmacy, or from my home shopping catalogue.

I was back to work by now. Fortunately as a counsellor and homoeopath I'm sitting down with my clients, but nonetheless it was hugely difficult to concentrate properly, and to manage.

In May 2002 I called the stoma nurse at the hospital and found myself unable to stop sobbing. I'd tried to stay 'strong' but I felt I could no longer cope. I'd gladly have gone back to an ileostomy bag, but realised my initial feeling of 'I can always go back' was not quite so simple.

The idea of yet more major surgery and another hospital stay appalled me; and how could I be sure things would not be worse afterwards e.g.. due to the adhesions. I felt caught between a rock and a hard place, helpless and hopeless. The nurse was wonderful, and promised to get me referred to St Marks hospital.

In some ways I feel admitting that I couldn't cope, that things were not getting better, was a kind of turning point. Rather than treating myself informally with the help of colleagues, I contacted a homoeopath and signed up with her. Since we were unable to meet for a few weeks she suggested I start using a remedy, Oak 6c, daily which soon started to help.

After a year of treatment I would say I'm about 85% better, and confident I'll keep improving. My journey has gone full cycle. I started by believing homeopathy and the holistic approach could cure anything, given enough commitment.

I nearly died in my efforts to maintain this belief and undoubtedly owe my life to surgery and the NHS (as my previous story detailed) I now feel that I owe my *quality* of life to homeopathy; some readers will probably hate this unscientific approach, but I don't care, I feel well and that is

what matters to me.

The treatment has made me aware of how my energy has been flowing, what parts (my bottom!) have always felt dead and somehow 'shutdown'. I feel in touch with sensations I've not had since early childhood, and am in no doubt that this energy 'blockage' resulted in my illness. I believe the reason we often continue to get problems such as pouchitis, is because the symptoms have been treated, but the real cause of the disease in the body remains unaltered.

My heart truly bleeds for those of you who have written to *Roar!* with such horrendous tales of suffering. I want to encourage you that healing *is* possible, but probably not via more drugs and operations, but rather through finding a good complementary health therapist that you feel you can trust, to help you navigate the bigger picture of why your body is so hugely uncomfortable.

Before I finish I'd like to share a couple of things that I've found helpful. I don't follow any formal religion, but I've found that if I'm feeling rough, if I lie down, relax and ask for help from the angels (love, God, Buddha, call it what you will) this never

fails to give some sort of relief. In addition it seems to give a sense of a template of health and free flowing energy that soothes my own somewhat distorted and crippled energy system. Since my state of peace and relaxation has far more effect on my bowels than what I eat, any means of calming my tensions has real benefits healthwise.

My final tip is: I'm sure most of us find straining hard to pass stools with a pouch is not helpful, and may well aggravate matters. I find standing touching my toes and any exercise that stretches the hamstrings is helpful to relax the anal area. Consequently, if I'm having trouble releasing my stools, I try to imagine I'm doing this sort of exercise and consciously relax and 'let go' of my buttocks in the same way while sitting on the toilet. More often than not this gives the desired result.

I'm happy for anyone to call me to discuss any of what I've written. Should you want to contact my homoeopath her name is Lee Pollack and she practises mainly in south London, telephone number 020 8691 5210. My own telephone number is 020 8292 3081.

## Please support the Red Lion Group

Registered Charity number 1068124



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**



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- Newsletter three times yearly with all the latest news, views and events
- Membership is £10 (£5 for hardship cases, and free for 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 little 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,

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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.

