

ROAR!

ISSUE 25 • SPRING 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).



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An Idiot's Guide to Pouch Surgery

To those of you who have read up on the subject ad nauseum and know your ileo-anal anastomoses from your restorative panproctocolectomies, bear with me in this article.

Not all of us know the fine detail, or want to! And even if we do, we have relatives who don't want bowel surgery as their chosen topic on Mastermind. They want a simple, straightforward explanation, and here it is.

That's my apology in advance for the lack of proper technical terminology in this article. Various eminent professors and bowel surgeons are no doubt going to wince at a few technical inaccuracies. But there you go, you can't please everyone. I'm aiming unashamedly for the crowd, here.

Pouch surgery is clever stuff, you've got to admit. Your surgeon goes in there with a whole set of instruments (thank goodness for the full anaesthetic!) and cuts out your large bowel, your colon. Whatever the problem was with your colon is now, theoretically, solved, on the basis that you no longer have the colon.

But now there's another problem.

The colon wasn't there to look pretty, which is a relief, because otherwise it would have lost serious marks in any exam. On the contrary, it had a number of important functions, not least of which was dealing with waste matter (poo, to the average layman). Stuff goes in at the mouth, so it has got to come out somewhere.

Take the colon out, and you need to find some alternative way of dealing with those other functions.

This is where the clever bit comes in. The traditional surgical approach is to provide an opening at the side of the body, and attach a plastic bag to it, into which the waste matter pours, and which is periodically emptied by the owner. A perfectly valid approach, which is still the most appropriate

form of surgery for some cases. It's called an ileostomy.

However, pouch surgery deals with the problem in a different way. Instead of the side opening and the exterior bag, it works on the premise that the body can be *fooled* into thinking it still has a colon.

The nearest bit of innard to the now removed large bowel is a section of small bowel. It has similar features, in that it is long, but – as the name suggests – it is smaller in width. But it's plenty long enough for you to be able to nick a bit for your pouch.



It can't, as it stands, simply operate as the waste reservoir in place of the large bowel. It is simply not wide enough. So, instead, the small intestine is looped together like a length of garden hose, and is cut and resealed like a Blue Peter project so that – say – 3 lengths of small bowel suddenly become one shorter but much wider bit of pseudo large bowel.

That's the point at which it gets christened a Pouch. It is then joined back up to the rest of your outward plumbing, so that what comes through the pouch comes out of your bottom, just like before. Cleverly, this pseudo-

bowel does adapt over time to mimic the action of the real bowel. That's why you can't judge the performance of your pouch immediately after surgery – it can take a couple of years to settle in to what it is now being asked to do.

There are different ways to cut the small bowel to fit, known imaginatively by such names as the J pouch, the W pouch and the S pouch. It's not quite like different hemlines each fashion season, but design trends – even amongst bowel surgeons – surely come and go! The J pouch is currently the

MPV of the pouch world, where the S pouch is a Ford Cortina. Popular in its time, but now a rarity.

Most surgeons these days tend to do a temporary ileostomy (that opening and external bag) once they have taken out the colon, while the new pouch inside is healing up. Some surgeons prefer to do a one stage operation, in which the new pouch is formed and is immediately put to work on your waste matter. In theory, it's a cost-

effective approach, as it cuts down on surgical costs.

However, there are additional potential infection risks with one stage operations, given the excreta which are going through an area which has just been operated on. That's not to say the two stage ones are a doddle, but they do give the body a bit more of a chance to heal itself before being asked to cope with this whole new, unnatural mechanism.

Anyway, at the end of it all, what you end up with is a shorter piece of plumbing, which has been adapted in function, and a long scar on the out-

side where they cut you open. Other than that, all your outward bits look the same. Unless you're in the habit of showing off your tummy, no-one would ever know you have had this major operation.

I have mentioned the primary function of the colon: providing temporary storage for your poo until the time comes to push it out. However, the colon does lots of other things as well. Slow-digesting items get their final crunch in the large bowel, when anything left undigested further up gets well and truly seen to here. The large bowel also reabsorbs water and salts into the body; colonic bacteria have a role to play in the production of vitamins K and B12; and there are possibly other as yet unidentified functions.

The pouch is designed to take care of the mechanical waste function. However, pouch owners should be aware that other functions may not be so successfully handled.

This explains why owners of pouches might be advised to have vitamin B12 injections over time: because their body no longer produces this vitamin itself.

Also, as the whole bowel length is considerably shortened, foods have less time in the digestive tract to break down. Stubborn things like sweetcorn and nuts would normally be effectively mushed in the colon but do not get the same hard treatment in the pouch.

This is why blockages may occur, and also why your need to use the toilet may be more frequent than that of others.

Water reabsorption in a normal colon is why non pouch owners do solid poos – all the liquid gets effectively filtered out, leaving only the sludge to come out of the bottom in – ahem – more compact form. However, for pouch owners the shorter transit time and the different makeup of the pouch means that there is a much greater degree of liquidity in their waste when it comes out.

I am told you should really savour (if that's the right word!) the last time you do a big "plop" before pouch surgery, because it is the last one you will ever do. Apparently, it is a curiously satisfying sensation, once you can no longer do it! Even though I am not personally a pouch owner, I think

I can understand that.

Because the liquid is coming out of the rear rather than being channelled back round the body, pouch owners also need to be very aware of the risk of dehydration.

It's not just a case of the water, but also the salts that need to be replaced ... at least, that's the excuse

they give you when they make you drink litres of that horrid rehydration solution! Brian made me try it once, when I showed insufficient sympathy for his ordeal. Never again, I can tell you. Just a sip was enough to convince me that if I ever had a pouch I would be very careful *never* to get dehydrated!

Cagney and Lacey

Red Lion Group member Tony Foxell sent in a fabulous little article from The Times about a Catalan custom which would certainly provide a talking point in anyone's home.

When you're setting up your nativity scene around the Christmas tree, if you live in Catalonia, there's an extra member of the cast to include, beyond the holy family, the angels, the wise men and the shepherds. He's known as the *caganer*, or *l'home qui fa ses feines* (the man who's doing his business).

This little man traditionally wears a red barretina (the Catalan beret), has a cigarette dangling from his lips and a piece of newspaper tucked under his arm, while crouching in the time-honoured way to have a poo. Those of you who have read Roar issue 24 will realise immediately that he must be suffering a bout of pouchitis! Hence the cigarette.

Other variations of the *caganer* figure also exist: nuns, priests, politicians and celebrities, especially anyone whose activities are disapproved of. When Luis Figo, a Barcelona footballer moved teams to arch enemy Real Madrid, he became a popular *caganer* figure that year!

Caganer experts insist that this figure is not disrespectful to the nativity scene: he is not part of it, but removed from it, behind a wall or tree so that he cannot see the birth of baby Jesus.

Some argue that it is one of the

many little "everyday" touches deliberately placed in the Catalan nativity scene, on a par with other country activities which are typically represented. Others argue that this little figure dates from pre-Christian traditions, and represents a figure putting



back into the earth what was taken from it, acting as a symbol of fertility and hope.

So, if you fancy acquiring a controversial piece to complete your nativity scene and provide an unusual talking point, hop on a cheap flight to Barcelona in December. In the square right beside the cathedral you'll find the *fira de Santa Llúcia*, which sells all those essential nativity characters, including our little *caganer*.

My Story...by Lizzi Rudoff

Before you read on, you should know that this is not about how I scaled Annapurna three weeks after my pouch was formed. Nor have I got any great tips about what to rub into your behind after a prawn vindaloo. This is about how I lost my pouch. So some of you might not want to continue.

I went down with UC nearly seven years ago, six weeks after the birth of my second child. After three years of constant cramps, blood loss, steroids and hospital stays, I had an emergency colectomy.

Coming to terms with an ileostomy, having a bag of poo hanging off my abdomen, is still - to me - the stuff of nightmares. I had always been someone who would run to be sick whenever the subject of cancer came into the conversation; who felt faint if shown pictures of prostheses.

Not only that, but I had always been so fastidious about the way I looked. I don't want to brag, but to be frank, I was classed as 'beautiful', 'gorgeous' - men would walk into lamp-posts gawping at me in the street.

Yet, suddenly, here I was, the owner of a nasty-looking pink bag and clip, familiarising myself with the terms 'flange' and 'stoma' - words I still can't say without a shudder of horror.

So it might not come as a surprise that I still keep the letter my surgeon sent me, confirming the joyful news that a date had been set for my pouch operation.

Everything, my whole future, hinged on my pouch being a success. I'd have my body back; I'd have back my femininity; I'd feel normal again; there would be world peace; Richard Gere would choose me as his leading lady in a remake of American Gigolo (well, perhaps not those last two).

But I could put the whole ghastly nightmare behind me forever. And although I knew well the statistics - that only 33% of pouches can be classed as real successes and 33% are disastrous, the rest being just about

bearable - there was no question about it: I was going to be in the top 33.

Nine months after my colectomy, I had pouch surgery. The operation went really well, marred only by the fact that I went and caught campylobacter (really scary food poisoning) five days after going home, and had to be readmitted. The real problems started about five weeks later, when I began to have a sensation that

Over the next couple of months my long-suffering, wonderful, kind, patient surgeon tried everything... and I do mean *everything*... to save my pouch. It appears that there was nothing intrinsically wrong with the pouch itself (and neither did I have cuffitis, since I didn't have a cuff). My anal skin simply seemed unable to tolerate the level of acidity that my bodily waste was carrying.

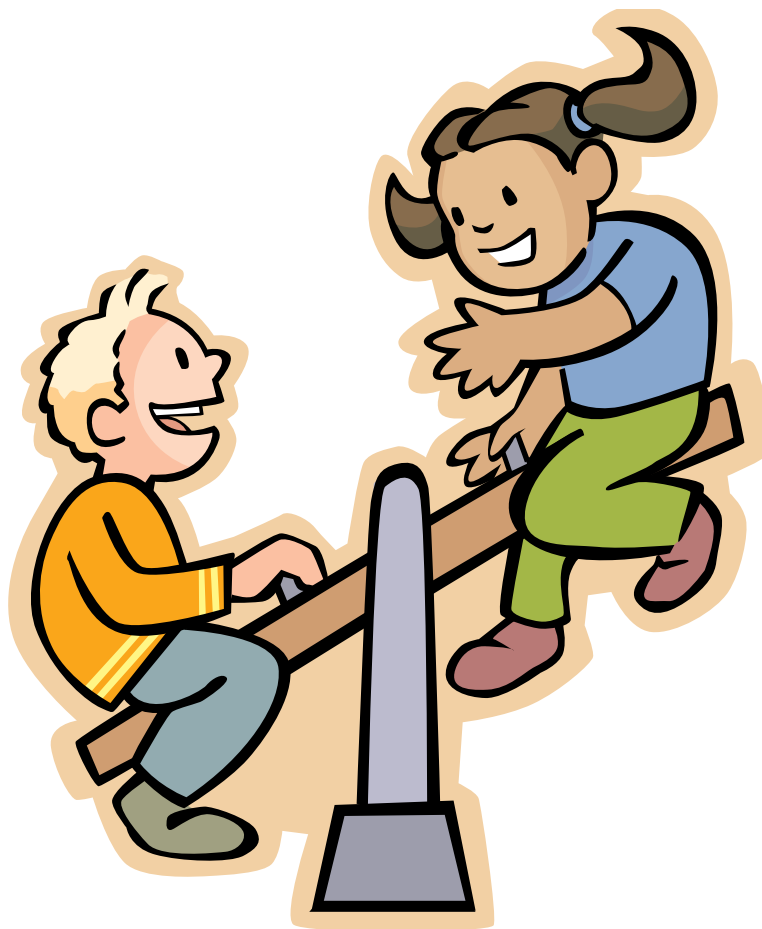
He tried emollients and unguents to reduce the inflammation; he tried drugs to reduce the amount of acid production; he even tried suturing a female condom inside my anus to act as a barrier. (This would have been a medical 'first', destined, no doubt, for a leading article in *The Lancet*, had the condom not started falling out one evening - and *you* just try explaining at 11.30 on a Friday night in casualty why it is that you have a Femidom stuck half-way up your jacksy.)

As a last resort, I was admitted and my pouch fitted with a catheter to bypass the anus altogether. This kept blocking up, and I spent one night in the loo, syringing the

appliance and sobbing with exhaustion. It was then that I knew I was heading for the operating theatre, and for what I dreaded more than anything - another ileostomy.

All was not yet lost. I had a *temporary* loop ileostomy, to let the pouch rest for a few months, then we would do some tests, and if all was well I could have my pouch back.

Months went by, during which I underwent some extremely useful counselling from a therapist specially trained in treating IBD patients, rec-



my anus was being permanently flooded with acid.

For some weeks I put this down to the itchy-burny discomfort that most pouch patients seem to suffer from time to time. But I was reduced to tears of misery just walking from one side of my kitchen to the other! And when, after a routine procedure, my surgeon remarked that it looked like someone had been putting a blowtorch up my anus, I began to fear something bad was about to happen...

ommended by my stoma nurses. And soon it was time to go back to hospital to begin testing my pouch.

I won't go into too much detail here (some of you might be eating); suffice it to say that the two weeks of two-hourly tests involved a catheter, a syringe, a pudding bowl and a kitchen sieve. Oh, and excruciating pain. It was some time during the middle of the second week that it hit me: if I were to keep this pouch, it would mean spending my life as an invalid. The game was up.

Strangely enough, once I knew deep down that my pouch and I were destined not to be together, it was actually quite a relief.

Since the whole process had started, this was the first moment that at least I knew where I stood. It wasn't what I had wanted, but there was no choice and I would just have to get on with it.

So I made two decisions; I would have the pouch taken away, and I would spend a small fortune on a fabulous new wardrobe (highly recommended treatment). After all, if I was going to look like a train-crash with my clothes *off*, I'd make sure I was going to look as good as possible with them on!

The new wardrobe was a great success; the pouch removal not so. My adhesions were so thick and numerous that trying to reach the pouch became too risky. And after many hours of surgery, they had to just sew me up again. Which means that I am, I think, almost unique in having both a pouch that will never be used, *and a permanent temporary* ileostomy.

My surgeon says he can operate on me again in a couple of years to remove the pouch, once the adhesions have matured. Will I bother? I do suffer from pouchitis, and it's a pain having to manage a loop ileostomy.

But somehow, whether the pouch goes or stays doesn't seem so important any more. I've gone through a difficult, sad, life-changing process in the past few years. But I've come out the other end - so to speak - and although it was hard, I feel strangely enriched by the experience, and rather proud.

And you'll never guess what - some bloke walked into a lamppost yesterday gawping at me!

Red Lion Group AGM and Information Day Saturday 12 April 2003

It only seems like yesterday that we had the last AGM and here we are just a few weeks away from the next one.

We have most of the speakers for the day and will be running similar workshops as last year. This is by popular demand as, following a consensus of opinion at the end of the workshops last year, many of the members found these particular workshops very useful but due to time restraints it was felt not all the ground was covered.

It is regretted that due to the high cost of the catering for food we are unable to provide this for free as in the past. In order to keep costs to a minimum and cover our overheads we have to make a small charge of £2.50. It is hoped that we will be able to provide some tea and coffee on the day. We are currently negotiating a reduction in the parking fees. Formal attendance application forms are enclosed with this issue of the newsletter - please send yours in as soon as possible.

As you will appreciate, all charities are feeling the pinch and ours is no exception. We recently lost, unex-

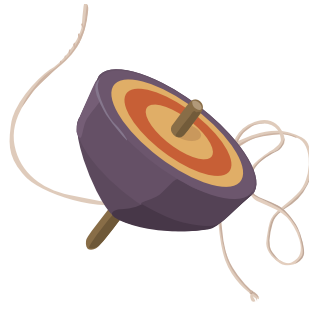
pectedly, the financial support of Custom & Excise who printed the last edition of *Roar!* due to restraints that have been imposed on them. This has been a great disappointment. To us and means we will now have to look for a new printer, which will be a huge cost to the group. However the *Roar!* is very important to the group and is our main focal point and we will strive to keep the issues going. Hopefully, by the time you read this we would have been successful

I must take this opportunity to thank all the committee members for their hard work over the past year and a special thank you to Morag and Brian Gaherty our unsung heroes for their tireless work over the years.

As I said in my letter to you earlier I welcome any contributions you wish to make to our letters page or you may even feel brave enough to write an article for us.

I look forward to seeing you at the AGM. If you have any problems, please feel free to contact me.

Mike Dean



Norfolk News

For the last 9 years, Sylvia Mist has been heavily involved in running a group for Norfolk pouch owners (and potential pouch owners), in conjunction with her local hospital, the Norwich and Norfolk. The group has its own identity but is still part of the Red Lion Group.

A few years ago Sylvia, with assistance from the Red Lion Group, gained sponsorship to train members on how to carry out visiting/counselling with patients.

It was her excellent idea to institute a regular visiting program at the hospital, which is still running to this day. In addition, the group holds regular get-togethers. It is probably fair to say that there are no other regions in the country where pouch

owners are so well supported at a local level.

Sadly, Sylvia is very unwell, and has had to step down from her position as Red Lion Group regional rep for Norfolk, as well as from her involvement with the local group, in order to concentrate on her own well being. The group will continue under the care of Tony Cates.

Tony has asked me to thank Sylvia for everything she has done for the group, not just as a rep but also as a good friend. On behalf of the committee, Sylvia, I would also like to thank you for your input to the Red Lion Group. We know that these are difficult days at present, and we wish you all the best in facing them.

Brian Gaherty

Letters

I have been rushed into hospital on 3 occasions this year with dangerous symptoms.

First blood test unsatisfactory, sodium level dangerously low, potassium dangerously high, blood pressure dangerously low. After 10 days in hospital, only to be rushed back 2 days later, even worse, and suspect kidney failure.

3rd visit – symptoms of a heart attack.

Investigation at the QE in Birmingham showed, the first results of a whole series of tests, that not only was I de-hydrated but massively so - level 10 might be someone wandering in the desert and I was level 8!!!.

I thought I was taking correct care of my pouch. It seems not. Hopefully this will be corrected with salt tablets. I also plan to not drink too much water but add fruit juices to avoid removing too many minerals.

Yours sincerely
Sandra Thomas

Dear Newsletter Editor

Congratulations on the new magazine format ... very smart, and it's good to know that you've been able to make arrangements for regular printing for the future.

I'm a so-called pouchie and had my job done at the Luton and Dunstable Hospital by Mr Novell and his team in August 2001. And I can say that apart from a few small problems things are progressing reasonably well.

I think that small tit-bits of experience that people write into you about are of great value to others. It can give them confirmation of something they were unsure of, or it can give them confidence when they find out that many people have experienced the same condition or symptom as they have.

For instance, Susan Walls' comment in issue 24 regarding the use of nicotine patches was confirmation to my daughter's friend with a similar experience of the effect that smoking has in holding back the messy outcome of having colitis. I hope you get more correspondence on this topic – it is most interesting.

I personally gained from a tip

given in the first magazine I received on joining the group.

The article by Sharon Hendron on endometriosis was very interesting to a friend of ours who has been experiencing similar symptoms, and it's of value to know possible alternative ways of dealing with these things.

There is now a great deal of information regarding pouches on the internet and recently my daughter entered a "chat room" of pouchies who were discussing their individual cases, and the pros and cons of various things.

Sixteen people were in the "room" and three of them talking from America ... amazing. Again, comments were made and information given that was helpful to others. It's a small world and getting smaller.

I hope more people write in ... just a post card would do, with just an item of info like "POUCHEES, TRY MARSHMALLOWS. THEY CAN REALLY HELP TO SLOW THINGS DOWN".

Keep up the good work. I look forward to receiving the next issue.

John Creasey



Dear Newsletter Editor

I need your help. Please can you print this letter in order to put me in touch with any ex-pouchies, by this I mean a person who, for any reason has

had their pouch reversed to a permanent stoma.

I am a sixty seven year old lady and am finding my 3½ year old pouch very difficult to live with.

My husband and I took a holiday in Spain last year. It was the first holiday taken since my pouch operation. Well, It (by "It", I mean the pouch) did allow me to walk around most mornings, but my afternoons were spent looking at the hotel room walls because of It's demands.

When at home, we are not able to enjoy an unplanned day out any more; the route must always be planned around the known toilets. I have bought a Radar key, and also use the disabled toilets, but because I don't look disabled I get challenged. All this I know can be tolerated, but I feel the pouch dictates so much that it restricts the freedom that a retired person should be able to enjoy.

Now we have the more important details. Unlike most pouchies, my pouch is not always loose and easy to empty. In fact, later in the day, every day, I lose blood when emptying the pouch. The output is so stiff that the straining required to pass enough to feel comfortable is what causes the blood loss. The straining also causes inflammation of various joints eg wrists and shoulders. I have to resort to drinking prune juice, but this gives me diarrhoea.

At times, a visit to the toilet can take up to half an hour. This is not very sociable when trying to entertain relatives or friends, and how do you deal with the same situation when visiting them?

Approximately every three months I get mild pouchitis and cuffitis, which is inflammation of the rectal-pouch join. This, I am told, will be recurrent.

I drink Yakult for the mild pouchitis and am prescribed colifoam enemas for the cuffitis. Colifoam is a steroid. I suffer with osteoporosis and spinal scoliosis, presumably caused by 29 years (off and on) of Predsol enemas as treatment for ulcerative colitis. It is well known that steroids thin the skin and bones, so I use this reluctantly.

I take a once weekly tablet of Fusamax for the osteoporosis. I am told it would also be helpful to the

bones to take calcium daily. However, calcium being partly chalk obviously makes the pouch output even more stiff, so I cannot take it. Any food containing calcium causes trouble, and in fact all the foods that other pouchees take to slow the pouch down constipate me.

Of course I realise that some of these problems will not affect a younger pouchee.

I have been given to understand that the pouch could take up to 15 years to work successfully. I shall be



82 years old then. This seems like a prison sentence to me – but what am I guilty of?

The pouch restrictions and difficulties have caused a lasting state of depression for me, and I haven't even mentioned the hair loss and joint pain.

If any person, male or female, has had a pouch reversal – successful or otherwise – would they please contact me? I am happy to pay the cost of the call. My telephone number is 01205 365291.

I need to find the courage to go for a reversal, and the peace of mind to know it will be of benefit.

Thank you in anticipation.

Yours sincerely

Mrs Yvonne Sharp

Ed note: Yvonne, we would strongly recommend talking to the pouch care nurse at St Marks to see if a second opinion might be helpful to you. Joanna Sweeney is currently on maternity leave, but is due back within the next month or so, and someone else will of course be standing in until then. The technique of biofeedback might also be helpful.

Ode to the NHS

Susan Walls reminds us just how lucky we are in this country

I've just come back from a year-long trip to the states – we lived in LA while my husband was making a US television show. Yes, we saw lots of movie stars; I'll tell you all about them in a moment. But first, I have something important to say. The NHS is brilliant. We must hang on to it. Private medicine doesn't work, and never can.

Most US insurers wouldn't even consider covering me or my husband, and the ones that would wanted a thousand dollars a month. Each. He has diabetes, I have a pouch after years of UC. Pre-existing conditions are not popular with insurance companies. So a trip to the doctors cost us a hundred and fifty dollars, up front. And that's just for 'hello'. If you need any tests, you pay extra. A night in hospital in LA costs eight thousand dollars, before treatment costs. No, I'm not making this up. You couldn't make it up.

A friend of mine here has a three year old boy, and she's still paying off his birth. She's still not quite sure of the details, but she thinks that he popped a lung because he was such a big baby, so he had to spend two nights in the specialist baby-intensive-care unit. The bill for that was twenty thousand dollars. She had insurance, but it wasn't a comprehensive policy – she only paid four hundred dollars a month for her health cover. (Most families I know in LA spend at least seven hundred.) So the insurance company insisted on a co-pay, which means that you get to pay part of the bill. But this is the really terrible bit: my friend had an epidural because the birth was so long and so painful. The insurance company insisted that she pay the whole cost of the epidural – eight hundred dollars – because it was a luxury, not a necessity.

And then, to add further insult, she got more bills from doctors she never even saw. Every doctor who went to the ICU to look at her baby billed her for a further thousand dollars. She has no proof that they were even there, or that they did anything

if they were there. She offers you this piece of advice: if you're ever in hospital in America, get a visitors' book, and make all the doctors sign in and explain what they actually did. Otherwise you'll get ripped off. As she says, once medicine becomes a money-spinner, there's no end to the costs you'll



incur.

I told my US friends that I spent two months in hospital once. Then I had two big operations. And because of my condition, I get all my drugs free. They just look at me and smile – surely that sort of thing could never happen in the modern world.

In Britain, there's a medical postcode lottery. In America it's more like healthcare Russian roulette. Health insurance is so outrageously expensive that many families just hope for the best. We met lots of people in LA who just insured the kids, and kept their fingers crossed that nothing ever happened to them, otherwise they'd lose their house and their car and everything they'd worked their whole lives to get. Forty three million Americans have no health cover.

Still, we did see some hot celebrities. I sat next to Elvis Presley's granddaughter at a beach party. My husband spotted Marlon Brando at our local Mexican restaurant, and we walked right past Bruce Willis on Santa Monica Third Street Promenade one Saturday afternoon (he's much smaller than you'd think). My little boy and I had coffee with the voice of JJ The Jet Plane (who also does Jimmy Neutron, Boy Genius). And the stuntwoman who taught Lucy Lui her whip skills for Charlie's Angels is wearing my old dress. But that's another story...

Book Review

Clear your diaries for March so you can settle down to some inspired reading.

And that's an order. For a book of rare beauty and distinction will be on sale that could revolutionise your views on pouches and proctology. The book, *The Good Gut Guide*, is written by the journalist Stephanie Zinser and has already reformed my eating, drinking and social habits.

Yes, Stephanie has performed a remarkable autopsy. She has dissected a scientific subject with skill, enthusiasm and humour, covering the treatment of butt pains, IBD, constipation, diarrhoea, ulcerative colitis, Crohn's and cancers clearly and readably, blending medical fact with specialists' views and patients' responses.

With an introduction by Professor John Nicholls, St Mark's clinical director, and an endorsement by Clare Rayner, Stephanie's book delves into an area that has achieved many breakthroughs in the past 40 years. She shows how the first pouch was developed by Sir Alan Parks, with the able assistance of a certain Mr Nicholls, and Professor David Lane's pioneering work on colorectal cancer. She also covers alternative cures such as flower and herbal remedies, gluten-free diets and colonic irrigation (or chronic irritation as it is sometimes known). I had it once at the Hale Clinic, the Princess of Wales's favourite therapy centre, and felt like a slightly damaged hot water bottle.

Two of the book's best sections are 'How to Get the Best from Your Doctor' and 'How Problems of the Reproductive System Can Affect Your

Guts'. As Stephanie points out, bowels may not be an obvious coffee-time topic, but they are unlikely to faze the average doctor. So, as she says, never be embarrassed to discuss your colon

problems with your GP, and while pregnancy and pouches can be uneasy partners, always contact your GP at the first sign of trouble. Many women with pouches have given birth successfully.

Stephanie has treated her subject with sensitivity and intuition qualities the average male

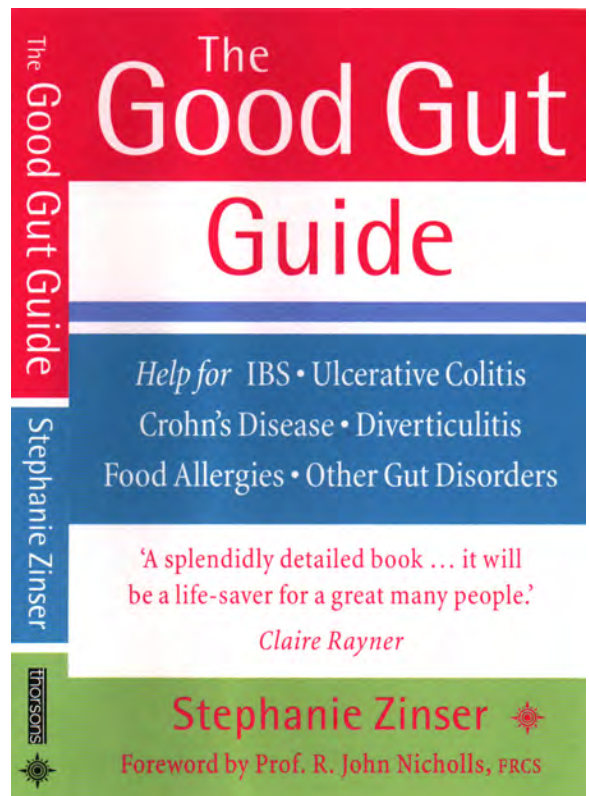
writer probably lacks. As an author and former pouch patient, I have thought about writing a similar kind of book several times, but my approach would be too dry and clinical. She has given both layperson and professional a humane guide with acute observations based on her study of psychology. She also passes on innumerable tips. Holidaymakers, for instance, should avoid bathing in untreated water or using ice cubes, as they may be made with tap-water; people with allergies should keep a daily food diary listing what they eat and how it affects them; and next time you go on a bender mix your alcoholic drinks with soft ones you'll

certainly appreciate it the morning after the night before.

The book is a personal crusade. Stephanie, who writes about health for the *Daily Mail*, *Evening Standard*, *The Sunday Times* and several magazines, noticed the first signs of ulcerative colitis when she was 25 and expecting her first child. But if she talked about it, she found people tended to shy away. When 11 years later and a mother of three she had a pouch operation, she still found the gut one of life's great unmentionables. As she says in the book: 'Talk destroys taboos. Information saves lives.'² So read on - it may well turn out to be the best £10.99 you've ever invested.

With its alluring, cornetto-coloured cover, *The Good Gut Guide* should be on the reading-list of patient, therapist, health visitor and GP alike. I think it will do very well. Just a gut feeling, mind. But we all know how persuasive they can be.

The Good Gut Guide (HarperCollins) by Stephanie Zinser, published on 3 March 2003, costs £10.99 and is available at all leading UK bookshops. You can also order copies from Amazon.co.uk.



Who Cares Wins

Of course, pouch owners are not the only people affected by having a pouch, particularly if it is a badly behaved one. Their family and the people who care for them are also affected. It can be highly stressful caring for anyone with any kind of disability or limiting factor, and it can be hard for the carer to get either help or support. With surgery like this, which a lot of people have difficulty talking about openly, it can be doubly hard.

There is a UK charity called Carers UK who might be able to help. Carers UK provides support to carers, whilst at the same time lobbying Parliament for improvements to benefits and the provision of services to carers.

Carers are defined as people who “look after family, partners or friends in need of help because they are ill, frail or have a disability. The care they provide is unpaid”. So, a nice wide definition reflecting the support that is actually given by volunteer carers rather than trying to pigeonhole them into some specific relationship category.

How can Carers UK help? Well, in a number of ways:

There are a number of information booklets available from them, including one called “How Do I get Help?”, explaining the carers assessment process. They can also provide you with information about getting respite care. Even carers need a break sometimes!

There is also a carers line which is open 10am-12pm and 2pm-4pm Monday to Friday on 0808 808 7777, which is a freephone number. Their website is www.carersonline.org.uk and their postal address is:

Carers UK
Ruth Pitter House
20/25 Glasshouse Yard
London
EC1A 4JT

Finally, members receive a quarterly magazine called “Caring”, which includes stories from carers to act as support and inspiration for others.



Milk and Two Sugars



Many of our members live in the Harrow area, and Christine Lawton is currently investigating the viability of holding periodic coffee mornings/social meetings at St Mark's Hospital to provide some active support for local members.

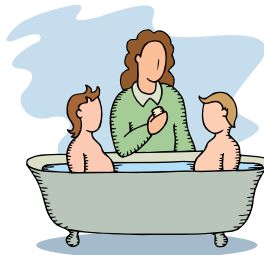
Biscuits, coffee and tea would be provided.

If you are interested in being coming along or helping out, please either phone or e-mail Christine (details on Committee Members' page).

Baby Baby

In a recent issue of *ia* Journal contains a very interesting personal story from a lady in her thirties called Lisa Coles. Lisa is very unusual in that she has had two babies, both by normal delivery, since having surgery to control her ulcerative colitis. She had the first whilst still an ileostomist and the second as a pouchie.

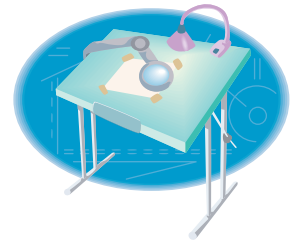
I mention this because she has specifically stated that she would be willing to answer any questions about her experience, and I know that there are female members of the Red Lion Group who would like to talk to her about this. If you have any queries for Lisa, please contact her via the editor of the *ia* Journal: Journal Editor, Mr John Small, 36 Yallop Avenue, Goreslton, Great Yarmouth, Norfolk NR31 6HD Tel: 01493 300999 or e-mail editor@iajournal.co.uk.



Let's Get Quizzical

Many thanks to Chris B for providing this little brainteaser.

- 1 Which US athlete has won eight Olympic gold medals?
- 2 Is Innsbruck in France, Austria or Germany?
- 3 When was the National Health Service introduced - 1940, 1953 or 1948?
- 4 Name the longest-serving British prime minister since the Second World War.
- 5 Name the world's largest freshwater fish



- 6 Who composed the Trout Quintet - Bach, Beethoven or Schubert?
 - 7 In which year was president John F. Kennedy assassinated?
 - 8 Who is the patron saint of Wales?
 - 9 When was the Social Democratic Party (remember them?) formed?
 - 10 Who discovered penicillin?
 - 11 Who wrote the poem The Charge of the Light Brigade?
 - 12 How tall is Mount Everest - 28,640ft (8,729m), 29,035ft (8,850m) or 27,900ft (8,504m)?
 - 13 Who said Veni, Vidi, Vici?
 - 14 Where is the Sea of Tranquillity - the Moon, South Africa or Canada?
 - 15 Who was the first man in space?
 - 16 Which planet is famous for its rings?
 - 17 Name the world's longest insect?
 - 18 In which year was British Telecom privatised - 1984, 1977 or 1990?
 - 19 Which playwright said: “Experience is the name everyone gives to their mistakes?”
 - 20 Name the oldest of these university towns - Oxford, Grenoble or Cambridge?
- Answers on page 14.*

The Bag Old Days

It is now seven years since Brian had his pouch surgery, and those 10 weeks when he had an ileostomy are a fairly distant memory. Looking at the latest issue of the *ia* Journal, it seems that things have changed quite significantly for ileostomists as well as for pouch owners.

One thing which caught my eye was the existence of a number of different brands of a fluid-thickening agent to be placed in the stoma bag. The idea is that a gel or capsule is placed in the bag before it is attached to the stoma. This reacts with bodily fluids when they enter the bag, absorbing the liquid and thickening the stools. The stated benefits are:

- Bag is less obvious under clothes
- Improved comfort
- No change in weight or volume
- Reduced possibility of leaks
- Reduced movement (and associated rustling sounds!) of the bag contents
- Reduced odour
- Eases the emptying and cleaning of the bag
- Reduces sore skin around the stoma
- Bag contents empty directly into the toilet
- Increased feeling of security, especially at night

Three brands advertised in the *ia* Journal are:

- Sorbion Sachet
freephone 0800 269 327 (a sachet placed in the bag)
- Oakmed Gel-X freephone 0800 592 786 (a small capsule placed in the bag)
- B. Braun Ileo-Gel freephone 0800 163 007 (no details as to what form the gel comes in)

All three suppliers offer a free trial of their product. I have no idea if it is then available free on prescription, but if it is half as good as the advertising suggests, I know that we would have considered it worth paying for. The embarrassment of living with a rustling pouch and the yuk factor with emptying it are memories that have not gone away for Brian. These thickening products address most of the concerns we had about an ileostomy for the ten weeks until it was reversed, and must make the possibility of a

permanent ileostomy less frightening.

After all, we all know that not everyone gets on with an internal pouch. A few people, as demonstrated amply elsewhere in this newsletter, have terrible problems maybe even caused by the pouch surgery they have had. If developments like these reduce or remove the *fear* of an ileostomy, which is often the major hurdle for a patient, then they can only be beneficial. I know that we hated the idea of a bag, but – had Brian had to



have one – we would have adjusted to it, and probably not found it half as bad as we would have thought. It was the fear beforehand which made the idea worse.

I'm not suggesting that everyone with a badly behaved pouch should start thinking about a permanent ileostomy instead. Only your consultant can advise you on whether it would improve or even change anything. But what I am suggesting is that those whose quality of life has not been improved, or has even been reduced, by the pouch might reconsider whether this is a price worth paying just to avoid an external stoma. If you've been having problems and are already having a temporary ileostomy while allowing a shell-shocked pouch to rest, these thoughts will probably cross your mind. After all, it's the best

time to find out whether you could actually live with a stoma.

One other issue which concerned us when Brian was faced with surgery seven years ago was the effect that the temporary stoma would have on our lovelife. The question of attractiveness to your (potential) partner has a huge effect on your confidence and, again, plays a major role in the fear of a stoma.

Having seen loads of medical-looking underwear for ileostomists, it is such a relief to see that nice and yet practical lingerie and swimwear can be designed for this market.

White Rose Collection is a small business, started in 2001 by a female ileostomist, Tanya Hutton, and her husband David, specifically because they were concerned at the lack of stylish underwear and lingerie for people in their circumstances. All the designs are tested on people with stomas, and if you are online you can see them on their website www.whiterosecollection.com (although I seriously doubt that any of the mannequins used for the pictures have stomas!). The Silk Collection is only for those with wads of money or who like to dream – I skimmed quickly past a camisole set at £145! But there are also lots of pretty garments in synthetic fabrics under £30.

They have designed a high quality, English-made range of female underwear for a wide age and size range, including briefs suitable for (ahem) romantic moments. All items have a special inner pouch and a higher waistline. Apparently this makes it possible to wear a larger range of outerwear, as the bag is better controlled and positioned. The range is shortly to be extended to menswear and childrenswear.

Finally, a percentage of their profits will be going to *ia*, for support and research. If you are interested to find out more, their number is 01202 854634 or you can e-mail them on info@WhiteRoseCollection.com.

Pouch Booklet on the Web

The very useful St Marks Information booklet, *Ulcerative Colitis: A Surgical Guide for Patients*, written by Prof Nicholls and Julia Williams, is now available on line.

You can find it at
www.stmarkshospital.org.uk/pdf/ulcerative_colitis.pdf

The booklet explains in very clear layman's terms the relevant anatomy, gives a description of ulcerative colitis and indicates when (and what) surgery would be warranted in the following cases:

- Acute colitis
- Chronic colitis
- Large bowel cancer
- Crohn's disease

We then get on to a description of the available surgery itself, including

- Restorative proctocolectomy with permanent ileostomy
- Permanent ileostomy
- Kock ileostomy
- Colectomy with ileo-rectal anastomosis
- Restorative proctocolectomy with ileal reservoir – the "pouch" procedure

Finally, the booklet covers expected results of surgery, to enable patients to assess the factors in the decision to be made. This section is split into:

- Complications of the pouch, both early and longterm
- Failure of the pouch
- Function of the pouch

The two main post-operative complications are adhesion obstruction caused by a kink and infection. Another major complication is some degree of breakdown of the ileo-anal anastomosis, which is normally minor and heals on its own, but may not.

Long term complications are familiar to many Red Lion Group members at some point: pouchitis, pouch-emptying problems, anal skin soreness and pouch fistula. The booklet contains tips and hints on dealing with these.

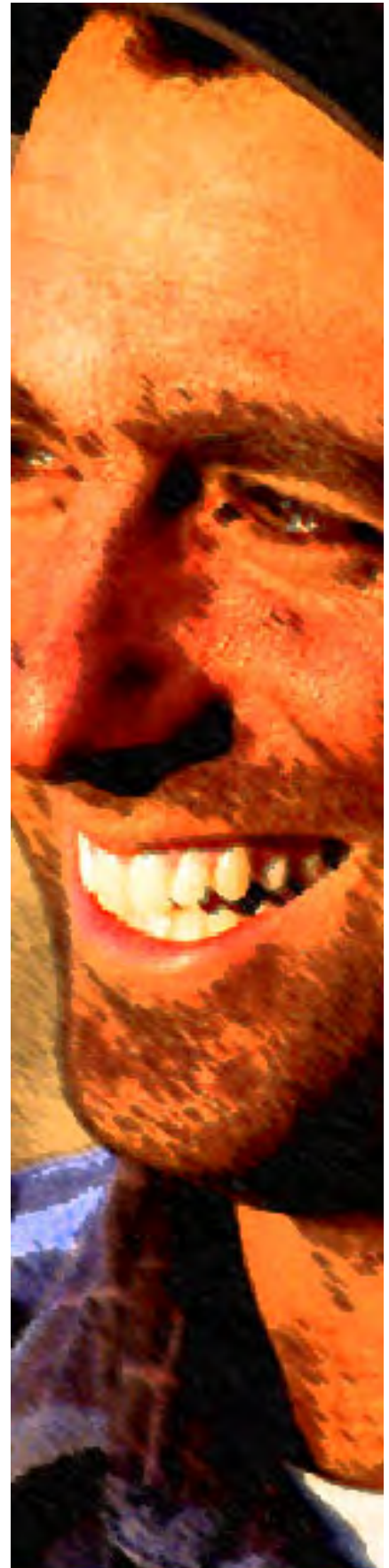
Pouch function is a catch-all term for frequency, urgency and conti-

nence. Guideline figures for frequency (number of trips to the toilet per 24 hours) are anything from 2-8 times, with a norm of around 4-5 times. The need for anti-diarrhoeal medication varies greatly from patient to patient, and the overall function of the pouch will determine whether it is necessary or not (usually in about 20-50% of cases).



All of these factors will have an impact on the final issue discussed: quality of life.

Overall, this is an easily-readable booklet which explains in everyday terms exactly what your consultant is talking about, and how you can help yourself to a better pouch. It is well worth a read. If you do not have access to the internet and would like a copy, just call the Pouch Care Team at St Marks on 020 8235 4126 and ask them to send you one.



Don't forget the AGM
and Information Day
Saturday 12 April 2003

Life as a Pouch Owner

If you are reading this article, it's a fair bet that you are either a pouch owner or very close to someone who is. Given that, you'll be familiar with the joys and sorrows of pouch ownership but, if you're anything like me, you still find it useful and interesting to read about other people's experience of a pouch. If not, stop reading now!

I had my second, successful pouch operation in summer 1998, 4½ years after the first, unsuccessful attempt which left me with an end ileostomy. So I have a very good basis for comparison between the two options, and I can now give an almost complete thumbs-up to the pouch.

The only advantage that I can think of for the ileostomy (and it is, admittedly, quite a big one) is that I felt very well – no attacks of pouchitis and good energy levels.

But in the past 4½ years, whenever I have felt really awful (and that was pretty often until quite recently), I have repeated to myself two mantras: ileostomy bags leak (at least they did for me, from time to time); and no more kneeling in front of dodgy loos (I never mastered the art of emptying the bag while sitting on the loo). Nor, apparently, have I mastered the art of writing without the use of parentheses...

I have a theory that the surgeons and nurses don't tell potential pouchees the truth about the post-operative recovery timescale on the grounds that no-one would go ahead with it if they fully understood how awful it is afterwards. Certainly my happy visions of being back to normal within two to three months were rudely shattered.

On the other hand, I was also told that my condition at 18 months post-op would be as good as it got, and that wasn't true either. I'm a lot better now than I was three years ago, two years ago, last year...even allowing for the odd bout of pouchitis. Fortunately, ciprofloxacin seems to work like a magic bullet, and I make sure not to go on holiday without a course of pills in my washbag, just in case.

So what is life like for me now, as a pouch owner?

I would still like to find some means of stopping the spread of poo beyond the confines of the loo: sometimes the only way I can empty my pouch is in a curious, bottom-in-the-

ing materials every morning, and it's a small price to pay.

On the food front, I have accepted that I will never again be able to eat anything containing chilli, which has an immediate, dramatic and painful effect on me and can make me ill for a fortnight or more.

The only other food that I avoid totally is apple peel (though the upset caused by this occurred a long time ago, so maybe it's time to revisit this phobia). Lamb is a bad idea unless it is completely lean, but I eat pretty well everything else that I want to. Sometimes I wish there were more forbidden things – it might help me lose weight...

For a long time after my operation I used to slather on the barrier cream at night, but now I find I hardly ever need it – only if I have an attack of pouchitis, with attendant difficulties in emptying the pouch, greater frequency and hence greater soreness.

I do, however, always use a lot of Johnson's Baby Powder after every shower or bath, with the aim of keeping the area dry, and I am convinced this keeps the skin in good condition.

On the pharmaceutical front, I only take Imodium as a last resort, if I get a real attack of squits, but this is probably only about once every two to three months. The only other pills needed are co-proxamol, which I take both for pain and for general

lack of wellbeing from time to time.

So yes, a pouch is worth it, and I only hope that it will last me out – another 40 years at least if I'm lucky.



air position which not only looks extraordinary (were anyone to be watching) but also has catastrophic implications for the area round the loo. But you get used to getting out the clean-

Editorial

Well, here I am again writing another Editorial, up against the clock. I've recently instituted a new way to train ourselves for the rigours of time-keeping needed for when Bob starts school in September: I set the timer on the oven to go off 15 minutes before we absolutely *must* leave the house. However, this system does not work so well when trying to write something for the newsletter.

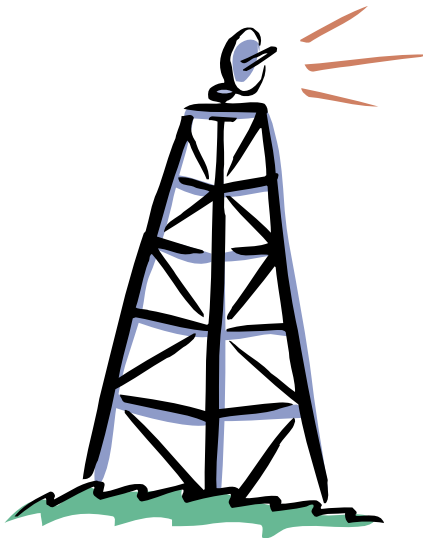
Instead, my "timer" is Mike Dean, whom I have encouraged to phone me up and nag on a regular basis. Not a natural nagger, I feel, he doesn't like this role, but it's a vital one. I keep trying to get out of doing the newsletter, so that someone with more time can take it on, but hints the size of houses don't seem to work. Maybe no-one else has any time to spare either. Ah well, I plod on.

But even determined nagging attempts can be foiled by things outside our control: I'm writing this on a laptop as my main PC has been out of action for over a week now - disastrous for the business, and no better for The Red Lion Group, as it held this last document, and therefore held up the whole printing schedule for Roar. It never rains but it chucks it down by the bucketload, I find.

As you will have read in a recent letter from Mike, we have had a blow on the printing front, having got all excited about our first full-colour issue last time. There was no way we could have afforded (or indeed justified) the cost of colour printing without a sponsor to pay for it. And then, out of the blue, a newsletter from the Alexandra Rose Day charity arrived which mentioned budget colour printing for charities like ours. And, lo and behold, we seem to be able to produce a full colour issue for almost the same price as we were doing in black and white, after all. Now all we have to

hope is that they can turn it round in time for us to keep close to the deadlines we have promised ourselves....

The next Information Day and AGM is almost upon us, on 12 April - I don't like to say how many weeks away that is, because it will seem even closer then. Mike and Christine have worked really hard to organise this, without as much help as we have normally been able to rely on from St Marks, with Jo Sweeney still away on maternity leave at present. Many thanks to everyone involved with the planning and to those who will be giving their time either to speak or help out behind the scenes on the day.



Last year's food bill, for some reason, was extortionately high relative to the number of attenders. I don't think this was a problem of people having booked but not turned up, so much as outrageous catering costs, one way and another.

This year, we have therefore arranged a nominal charge of £2.50 per head, which will cover necessary costs (you will appreciate that we need to ensure the availability of toilet cleaners on the day, for instance!) and tea or coffee. Please note that lunch will *not* be provided. Instead, you are welcome either to bring your own food, or to make use of the restaurant facilities on site. In this way, we hope to keep a tighter control of the costs of the event than has been possible in previous years.

The booking forms for the day are enclosed with this issue of the newsletter, and we need you to return them by 31 March to the Chairman (address on back page). I do hope you will be able to come. It is usually a very enjoyable as well as informative day, and a good chance to talk openly about issues which concern you as a pouch owner (or partner) with others in a similar situation.

My Story...by Tim R.

The only times I am reminded of my ileostomy these days are when I feed our cats, Molly and Charlie. The process of squeezing cat food out of the new Whiskas sachets is not that far removed from emptying a bag. Occasionally I dream at night that I still have a bag, but that happens rarely: it is more than ten years since I had my final closure operation at St. Mark's Hospital.

In those ten years I have enjoyed all sorts of new activities, most of which I probably could have done with a bag, but some which I felt I could not. I had an ileostomy bag for five years, and in the euphoric aftermath of my closure operation I had a strong desire to take all my clothes off at parties and go running down the street stark naked. After all that time living in terror of someone catching a glimpse of my bag, I did not find the prospect of inadvertently revealing my natural bits at all embarrassing.

Fortunately (for the general public) I have not been streaking; my wife does tell me off for not making enough of an effort to conceal my nakedness when getting dressed in the morning if the curtains in our bedroom are open, but we have not had any complaints from the neighbours yet.

Streaking aside, my two favourite new post-bag passions are playing rugby and scuba diving.

I am one of those lucky people who have always had an urge to go scuba diving ever since I was a child watching nature programmes on television. For a few years after my ileostomy operation I was banned from diving by my doctors because I picked up an pulmonary embolus while recovering from my colectomy.

A pulmonary embolus is a very serious condition brought on by deep vein thrombosis. A blood clot forms in your leg and drifts up towards the top half of your body. If it lands in your brain you can suffer a stroke. Fortunately mine landed in one of my lungs. Even more fortunately I dodged the 10% chance of dying from it.

I think the reason I developed a blood clot in the first place is that opposite my hospital bed was a poor man who had just had one of his legs amputated. The physiotherapist advised my after my operation to wobble

my legs around and she showed me several exercises to keep the blood flowing. But the first time I perched myself on the edge of my bed and stuck out my legs to wave them around in the air I glanced over at the poor chap opposite.

He looked at my two legs wistfully and I looked guiltily at his one leg. I didn't do any more exercises after that and paid the price dearly. Developing a pulmonary embolus almost killed me and caused me to stay in hospital months longer than I need have. If you are reading this article while recovering from an operation please learn from error: pay heed to your physio and make sure you wiggle your legs round vigorously and often! If there are any people on your ward with missing limbs, please ignore them.

So after endless chest X-rays and doses of filthy flucloxacillin I was released from hospital with a stern order never to take up scuba diving. The theory was that the injured part of my lung might rupture while breathing compressed air.

Five years later I underwent a pouch operation with loop ileostomy and six months after that I had everything plumbed through and closed up. My pouch worked perfectly and I have had practically no trouble with it ever since.

Not long afterwards I ended up sitting next to a GP at a wedding. I regaled the poor fellow with my full medical history. When I got to the end I told him that the thing I hated most was that I was unable to learn to scuba dive because I'd had a pulmonary embolism. To my astonishment he told me that he had recently signed off a patient to go scuba diving who had suffered from the very same condition.

I subsequently learned that the rules about diseases that prevent you from scuba diving have been relaxed over the years. In the sixties you practically had to pass an army medical to learn to scuba dive as it was considered an extremely hazardous sport.

With the huge advances made in scuba diving equipment and training over the years these days practically anyone can learn to dive. Obviously if you have, or have had, anything wrong with your heart or lungs you should seek medical advice before having a

go. In my case I was signed off by a special diving doctor. My pulmonary embolus had cleared up more than five years before and I was in rude health. After one last chest X-ray to make sure my lung looked fine I was signed off and ready to learn to dive.

I joined the local branch of the British Sub-Aqua Club (BSAC) in Putney and spent an hour in the swimming pool at Putney Leisure Centre every Tuesday for a couple of months learning to dive. The training is pretty straightforward. Statistically scuba diving is an incredibly safe sport – far fewer people hurt themselves scuba diving than do horse riding, yachting or playing rugby. But you need to



know what to do in the unlikely event of something going wrong. You also need to get to grips with some basic physics to understand how to avoid harming yourself breathing compressed air underwater where the pressure is greater than walking around on land. This is taught in a series of lectures and there is some background reading.

By Easter I had passed an assessment of my skills in the swimming pool and passed the theory exam. I was all ready to go diving in the sea. I signed myself up for a club trip to Swanage and spent the week before in an extremely apprehensive state. With hindsight I think this was very healthy. Diving is potentially hazardous and you have to be well prepared and cautious. A gung-ho attitude can be fatal and you must be careful not to go beyond your limits.

My first dive was under Swanage Pier and it was fantastic. The dive was relatively shallow – around 5 metres, or 15 feet – so perfectly suited to a beginner. There was plenty of marine

life and odd pieces of junk that people had mislaid while walking on the pier itself, including a wrought iron bench. I found that diving is a similar experience to snorkelling, except that you have total freedom to move in all three dimensions at will and are rather more encumbered, especially when diving in the sea around the United Kingdom where you need to wear a thick suit to keep out the cold.

Since then I have completed over 300 dives, mainly around the UK but also abroad in warm clear water. I am absolutely hooked. I even started training other people in my club and became a fully qualified instructor.

As well as the feeling of freedom gliding like a bird in three dimensions, I love diving because of the sense of awe at seeing things under the waves that are normally inaccessible to human beings. It is always a thrill to explore a shipwreck or encounter sea life in its natural environment instead of laid out on a counter in the local supermarket.

As far as the pouch is concerned it hasn't really affected my diving. For some reason my frequency of going to the loo tends to decrease sharply when I'm on a diving trip. This may be because there are fewer opportunities to use the loo, or because the opportunities are not as convenient – the loo on a boat is called a 'head' and it takes skill and concentration to empty ones pouch over it when the boat is rolling around in a swell having peeled away enough of your suit to expose your backside. It may also be that spending an active day outdoors messing around on boats and getting in and out of the water makes my bowels operate more sedately because my body is concentrating on keeping warm.

So if you have ever fancied learning to scuba dive but were put off because of your pouch I urge you to think again. You should consult your doctor if you have any concerns and make sure you declare your full history on any medical form you fill in. To find your nearest diving club you can phone the British Sub-Aqua Club on 0151 350 6200 or visit the website at www.bsac.org. To give you a flavour of what it's like to join an active and friendly diving club visit the website for my club, Putney BSAC, at www.putneybsac.com.

Will It Ever End?

If you're nervous about having a pouch, this article is not going to reassure you. However, it is important to know about the experience of someone whose pouch surgery experience has been pretty awful so far, so that you see both potential sides of the decision you take. I must warn you that this story makes extremely uncomfortable reading...

April 2002

It all began while I was carrying my daughter Alana. I started to lose a lot of blood from my rectum during my pregnancy in 1994, and was informed by my GP at the time that I had "piles, a common thing during pregnancy, nothing to worry about". Other than that, I was fine, a little tired, but that is to be expected, isn't it.

I had a beautiful baby girl on 23 September 1994, but I kept losing a lot of blood rectally. I then began to feel very tired and was going to the toilet a lot, as blood would just ooze from me. I also lost a lot of weight and suffered from diarrhoea most of the time.

I had changed doctors by this time and my new GP was not happy with my health at all, so he referred me to see a consultant at Barnsley General Hospital, where – after tests – I was told I had ulcerative colitis and put onto steroids.

The steroids only made me fat, and in July 1996 I was admitted into hospital for more tests and a blood transfusion (the nurses told my husband that I had lost above half my body's blood and they were surprised I walked at all, even unsteadily, onto the ward). I spent a full week in hospital then came home for two weeks before I had to return for my first operation.

During this operation, my colon was removed and a pouch (J, I was later told) was formed from part of my small intestine. I had an ileostomy to give this new pouch time to heal and was told I would have another, but much smaller, operation in about six months. Things did not go to plan and I had to have my second opera-

tion earlier than expected due to pain from adhesions. During this operation the adhesions were freed, and it was noted that there were some large cysts on my left ovary, which could also have contributed to the pain I was having before this operation. However, the cysts were left alone and the ileostomy closed.

Again, things did not go well. I was at the toilet most of the time as my pouch

another ileostomy to give it time to rest. I was still in pain and after one more operation during which my second ileostomy was reversed, my surgeon referred me to the Royal Hallamshire Hospital in Sheffield.

There I was to see a new consultant who put me through all the tests I had had at Barnsley and more besides. After he got the results he was not happy with my health and the level of pain I was in, so in January

1999 he operated on me for the first time (my fifth operation). I had to

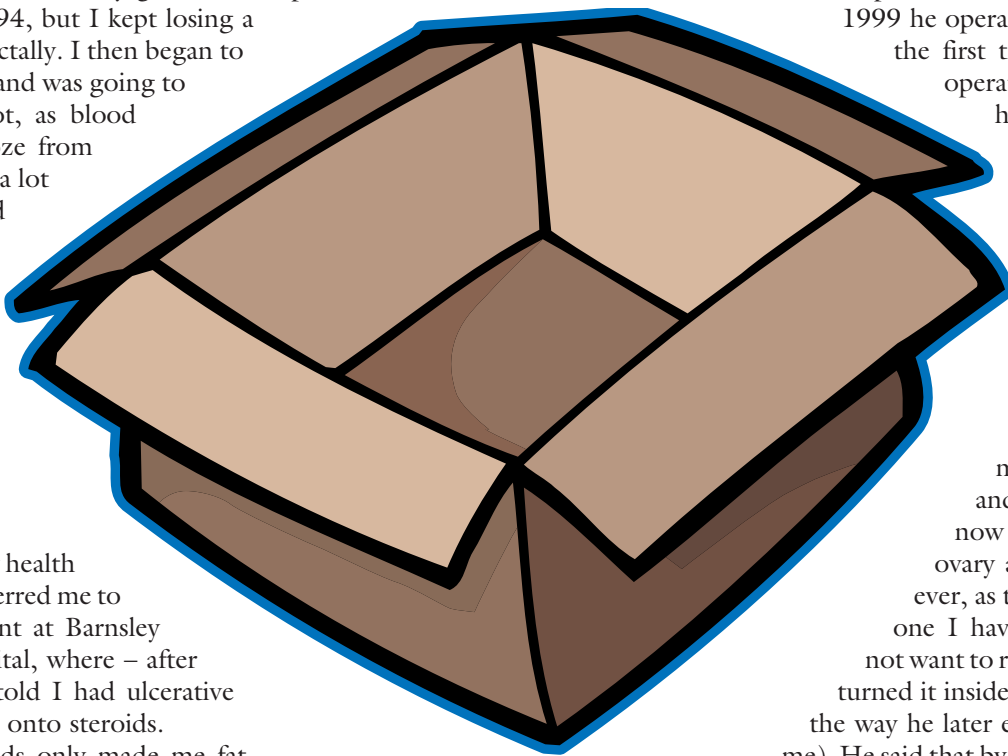
have another ileostomy as he found a fistula (a track of infection) which went from my pouch to my bowel.

He also freed more adhesions and found cysts now on my right ovary as well. However, as this is the only one I have left, he did not want to remove it so he turned it inside out (that was the way he later explained it to me). He said that by doing this the cyst could not come back.

It was decided to leave me with this ileostomy for twelve months. Even though I was not pain-free and was still quite ill by normal standards, I was better than I had been for some time.

My reversal (operation six) should have taken place in January 2000, but was cancelled due to a shortage of beds. It was then discovered that I had more infection. My right ovary was also a problem now, with new cysts on it, so my operation was put on hold for a while to try to get rid of the infection before surgery. The reversal did go ahead later in the year but things still did not settle down.

I was now emptying my internal



was

on overtime and I was losing blood again. My weight dropped and I was ill all the time (pouchitis). My surgeon decided that he needed to do more tests, which seemed endless.

It was very hard; my husband had to finish work to look after me and our daughter, who was about two years old by then. After lots of tests, which were degrading and very painful, it was decided that I needed more surgery.

Operation three. This time the surgeon removed a ball of pus which he said could only have been my left ovary, which had become very infected. There was so much infection (also in my J pouch) that I was given

pouch 30-50 times in 24 hours. My bottom was very sore and the pain in my stomach was intolerable most of the time. I could not go far from a toilet and was incontinent both by day and by night, which was very embarrassing.

I kept going to the hospital in Sheffield for tests and treatment, but nothing seemed to help. I was on enough codeine to bung up an elephant, but I was still suffering with diarrhoea.

Then in December 2001, I had a blockage in my bowel. I was admitted to Sheffield Hospital, was put on a drip and had a tube put up my nose down into my stomach. I also had a few other attachments and was allowed to drink only 25mls of water per hour, no food. It took nearly a week but it worked. The blockage cleared and I was allowed home without having to go to theatre.

I stopped taking my medication with codeine in when I became blocked and was now afraid to take it in case I became blocked again. It did not seem to make any difference. I was still going to the toilet 30-50 times. The pain in my stomach never went away.

I did everything the hospital suggested, watched what I ate and what I did. I had one sprout with my potatoes, carrots, neat and Yorkshire pudding for Christmas dinner but then I was ill for the rest of the day.

In February 2002 I was rushed back into hospital again with another blockage. This time I was not lucky, and on Valentine's Day I had to go to theatre. It was operation seven, and I was warned that I may come round from surgery with another ileostomy, but they managed not to do this. However, they found more adhesions, an abscess and more infection, which had narrowed the bowel and caused the blockage. They also noticed that my J pouch had been formed low down closer to the rectum than they would have done it, and its shape was a little irregular.

At the time of writing (April 2002), I have got an appointment to go to see my consultant later this

month to discuss what to do next, and he will tell me what he thinks.

But they are talking of more surgery and I do not think I can cope

been here now if I had not had surgery.

For six of the seven operations I have had, I have been cut from my rib cage down to my pubic bone. This last operation had about 40 staples down my stomach. The nurses said they wouldn't hurt when they came out, but what do they know, I asked then, and none of them had had them. It did hurt.

The other times I have been operated on, I have had a bead at the top and bottom of my wounds that have just been cut off and the stitch inside left to dissolve.

The first time, a nurse at Barnsley Hospital pulled it through, not knowing she should not have done; it was my first operation, I did not know either. Two of my ileos-

tomies have been on my right side, and I now have an indented X to mark the spot.

The third ileostomy was on my left side. My stomach looks like a



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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

rounded battlefield and if you watch it you can see my bowel moving around inside. It is still very painful and I am still incontinent and a very frequent visitor to the toilet. I have even had a toilet cubicle fitted into my bedroom.

I also suffer from diplopia (constant double vision) and very painful joints (knees mainly; they also give way on me and I have been known to fall if unaided).

My daughter Alana is now seven years old, my husband is still not able to work due to my health and we can still see no end to this.

December 2002

Over the past few months I have not been admitted to hospital again, but I have attended a lot of outpatient appointments and had yet more tests. I have avoided doctors on bad days, for fear of being admitted.

My consultant has suggested starting all over again, with the formation of a new pouch, as I have pouchitis yet again and my pouch has definitely been formed in the wrong place and is an irregular shape.

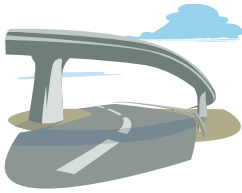
However, they may not be enough of the higher intestine left to form a new pouch, as so much has been removed in the past. He says there is a 50:50 chance of it working.

He has now said that under another surgeon's approval he would remove my last ovary, and at the moment I have asked if this could be possible, as then I may manage with my pouch better without the added paid of that.

I am also waiting to see someone else about my knees to see if some of the problem I have with them is related to my bowel condition.

I am happy for this to be printed in Roar to show that sometimes there are problems. I do not want anyone to be put off trying by my letter, but just to be aware of the risks. I am happy to reply to any letters forward to me by the editor.

Ed note: if you would like to communicate with this member, please send a letter in an envelope marked "Royston Lady" and we will forward it for you.



Don't forget the AGM
and Information Day
Saturday 12 April 2003

Fund Raising at the AGM/Information Day

As at the 2002 Information Day, Christine Lawton will kindly be running a plant stall. She has been planting and growing things for some months, so there should be a nice range of things to buy, including some vegetables. If you are a keen gardener and want to bring any of your own items for the stall, please feel free to do so.

There will also be a tombola stall, with tickets very reasonably priced, for a range of prizes.

All funds raised from these two activities go directly to the Red Lion Group, so do please come along and support them.

In addition, we hope to be selling Alexandra Rose Day Spring raffle tickets. The cash prizes on these are very generous, and selling these tickets enables us to offer some top potential prizes for you.

Something like 75% of the ticket sale income from the Spring raffle is directly retained by The Red Lion Group, with the balance going to the ARD charity to cover the cost of the prizes and the administration. In this way, the charity is able to lend its name to financially support small charities like ourselves.

Jolly good idea by the late Queen Alexandra, if you don't mind me saying so.

Answers to Quiz on page 7
1 Carl Lewis
2 Austria
3 1948
4 Harold Wilson
5 The surgeon
6 Schubert
7 1963
8 St David
9 1981
10 Sir Alexander Fleming
11 Alfred, Lord Tennyson
12 29,035ft (8,850m)
13 Julius Caesar
14 The Moon
15 Yuri Gagarin
16 Saturn
17 The stick insect
18 1984
19 Oscar Wilde
20 Grenoble

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** To fill this position please
contact the secretary, Christine
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Join the Red Lion Group

- Quarterly newsletter with all the latest news, views and events
- Membership is £10 (£5 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 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,



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.



